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Applications of Family-Centred Care in clinical practice

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Applications of Family Centred Care in clinical practice

Research suggests that families whose children have learning disabilities (LD) have limited service contact and when they do access professional support, it is unclear what intervention approaches best meet their needs. This thesis explored the service contact of children with LD, controlling for psychiatric diagnosis, and explored parents' views of an IY parenting course intervention. A review explored the key ingredients of parent professional partnership (PPP).

A secondary data analysis of a nationally representative sample of children in the United Kingdom found that children with LD had limited service contact. However, when children with LD had concomitant psychiatric diagnosis, there was no evidence they experienced less contact with specialist mental health services than children without LD. The main correlates of service use were gender, psychiatric diagnosis, LD and maternal emotional disorder. The review of PPP similarly found that providing emotional support to parents was important. Other key themes were negotiating power dynamics, establishing interpersonal relationships and consideration for the child. These themes were echoed in a focus group with parents who had attended an IY parenting course provided by a Specialist Children's Service. This intervention was effective in reducing some child problem behavior.

The emergent themes are related to the Family-Centered Care (FCC) approach, which includes concepts such as collaborative decision-making, empowerment and partnership.

The discussion paper considers the implications of the thesis findings for engaging parents with services, delivering interventions and refining the theory of FCC.

Review

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Top

The evidence base for the key ingredients of effective parent-professional partnership when children have a learning disability.

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Key words: Parent-Professional Partnership, Family-Centred Care, Learning Disability

Abstract:

Background: Parent-professional partnership (PPP) is a fundamental part of family-centred care. Several qualitative studies have examined parents' and professionals' view of partnership behaviours when children have a learning disability (LD). However, as the findings of these studies have not been collated or critically appraised, there appears to be limited insight into the key ingredients of such PPPs. To address this deficit, a review of qualitative studies of PPP in child LD services was conducted.

Methods: Two databases and science direct were searched for all published papers and references in relevant papers were reviewed. This found 108 papers and 29 were relevant to the review. Eight papers were excluded after the methodological quality of papers was evaluated using the Critical Appraisal Skills Programme tool (Public Health Research Unit, 2006). The key topics discussed by participants were identified and compared across papers. These topics were assigned titles that summarised the material discussed.

Results: The main topics discussed in the papers were: negotiating power dynamics, establishing an interpersonal relationship, emotional support and consideration of the child.

Conclusions: A tentative model for effective PPP in child LD services is presented and the discussion highlights how children's and fathers' views remain unrepresented. Additionally the heterogeneity of the samples and the need for a variety of partnership models is discussed.

Introduction:

Family-Centred Care (FCC) is promoted in United Kingdom (UK) government policy but the evidence base for its ameliorating effects in the UK is not extensive. The core concepts of FCC include collaboration, joint decision-making, support, sharing information and empowerment (Dunst et al, 2002). Parent professional partnership (PPP) is critical to FCC (Franck & Callery, 2004) and is endorsed in UK legislation. For instance, Every Child Matters (Department for Children, Schools and Families, 2003) dedicates a chapter to the importance of supporting parents and standard two of the National Service Framework for Children and Young People in England (Department of Health, 2004) similarly promotes partnership. PPP has different meanings across professions (Swain & Walker, 2005) but a review of the various definitions suggests a number of key attributes are referred to: caring, empowerment (McKlindon & Schluter, 2004 citing The Children's Hospital of Philadelphia, 2001), mutual respect, negotiation, sharing (Griffiths et al. 2004 citing Pugh et al. 1987), mutual co-operation (Betz, 2006 citing Houghton and Mifflin, 2000), respect (Farrell et al. 2004), listening, openness, consensus (Sloper, 1999) and joint working, sharing and equity (Morrison, 1996).

PPP receives greater emphasis when the possible options and implications are more complex and serious (Gabe et al. 2004), such as when a child has learning disability (LD). Although PPP seems appropriate when working with families where the child has LD, it is difficult to implement (Lindblad et al. 2005b), because there are multiple models of PPP (Farrell et al. 2004) and partnership processes are often unarticulated and unexplained (McIntosh & Runciman, 2008). Models of PPP in LD services rarely cite research to support their conceptulisation (Coyne & Cowley, 2007 citing Leez, 1998). An exception is Dunst et al's. (1988) model of the different helping styles and roles help-givers can take. However, they referenced only two case studies to support this model. In other services the literature has been reviewed to define key attributes of PPP. For example, Bidmead and Cowley (2005) reviewed health visiting research and proposed eleven attributes of partnership (Table 1).

Recent qualitative research has explored parents' and professionals' perceptions of what is important in PPP when the child has a LD, but the findings of these studies have not been collated to provide insight into the key ingredients of partnership. This paper will review the qualitative studies of PPP in LD services. As this is a new endeavour, the ingredients found will be compared with Bidmead and Cowley's (2005) eleven partnership attributes. Any similarities will provide evidence for key PPP attributes across different service contexts.

Methods:

The research question specified the setting (LD services), participants (parents and professionals) the area of interest (partnership) and the purpose (finding key ingredients). Web of Knowledge and CSA Illumina Social Sciences were searched for all published papers. Broad search terms ('parent professional partnership' and 'parent professional relationship') were used. The terms were then refined by adding 'Disab*' 'Retard*' 'Handicapped*' 'Autis*'. An additional search was conducted via Science Direct and the

200 most relevant titles were scanned. The references of relevant papers were also reviewed. Qualitative papers were reviewed if they indicated children had a LD. Papers focusing on diagnosis without applying this to ongoing partnership or interested in partnership in education were excluded, as the school and diagnostic contexts do not readily generalise to other PPPs. Papers not published in English were omitted (Figure1).

Papers meeting the inclusion criteria were reviewed using the Critical Appraisal Skills Programme tool for qualitative research (CASP: Public Health Research Unit, 2006). The CASP defines 10 areas that good qualitative research should refer to. For this review the papers were awarded one point for each area they provided sufficient information about. The author rated all the papers and six papers (representing high, medium and low ratings) were scored by a second reviewer. There was 90% item-by-item agreement, with disagreement only occurring when papers received mid-range ratings. As agreement on paper ratings (within one point) was 100%, the ratings given by the author were judged sufficient. Eight studies with a CASP rating below five were excluded.

There are several methods that can be used to synthesise qualitative data. This review wanted to extrapolate the key themes, so a narrative method was not sufficient. As the review did not aim to test a theory or hypotheses a realist synthesis method was inappropriate and it seemed premature to develop a data extraction tool to enable a meta-synthesis to be conducted. Thematic or content analysis could have been employed but the review aimed to summarise the key ingredients of PPP for LD services, so it had a framework within which to synthesise the findings. Ritchie and Spencer's (2002) framework approach facilitates such service development initiatives. This method is atheoretical, which was appropriate as the papers reviewed included different qualitative approaches, and the analysis process is clearly specified so replication is possible. There are no contraindications in this approach to including only papers that meet a quality criterion and adaptations of this approach have been used in other systematic reviews (Page & Thomas, 2009). The analysis conducted was informed by the framework approach and as the papers were read, notes were made of the topics discussed by participants and representative quotes to summarise the views expressed were recorded. As the papers had different aims, authors' theme titles were not the best source of information and more than one over-arching theme was often evident within author's themes. However, 70/88 author themes could be grouped under the key topics.

Results:

The 21 studies predominately used semi-structured interviews and the most frequent methodologies were grounded theory and interpretative phenomenological analysis. There was one case study and one paper which analysed case note correspondence. Studies spanned a broad time period (1988-2010) but the content discussed was similar, except from more recent interest in children's roles in partnerships (Table 2)

Papers reported data from 521 respondents, of whom 104 were professionals and 421 were family members. Figure two demonstrates the range of respondents represented (Figure 2).

‘Children’ ranged from 0-37 years and seven papers spanned large age ranges. Four papers covered pre-schoolers, three covered five-11/12 years, one adolescence and six papers did not specify children’s ages. The child’s diagnosis was not always stated but a broad range of difficulties was included, and some children may have had solely physical disabilities. Excluding the case study, only four papers focused on single diagnoses (two considered cerebral palsy and two LD). The range of diagnoses included is evident in figure three (Figure 3).

The analysis revealed that five topics were discussed across a significant number of the papers (Table 3) and these are discussed below.

Negotiating Power dynamics

Parents

Power dynamics were evident in initial encounters with professionals. During assessment parents’ constructed professionals as having privileged access to information and control over its disclosure. Maintaining partnership was construed as crucial to receiving a service, so parents’ believed they had to be co-operative and were hesitant in making demands (Avdi et al. 2000). This discourse study assumed parents’ accounts unfolded in a society that was uncertain about whether professionals’ views should be prioritised because of their expertise. This assumption may have influenced the authors’ analysis, as the assumption was closely linked to emergent themes.

Parents remained aware of power dynamics in partnerships. Even if relationships were positive, parents felt vulnerable and few disclosed everything that concerned them to professionals. This was summarised by a respondent commenting: *"..we don't say anything because I don't want anybody to have hurt feelings and then inadvertently, I don't think purposefully or anything like that, but take it out on him"* (Watson et al. 2006, p.656). The interviewer in this study told respondents they themselves had a child with disabilities and this may have increased parents' confidence in expressing their opinions. However, one inclusion criteria was that the therapist felt the family would be responsive, so the sample probably had good engagement with services.

Some parents sensed a lack of control: *"...you can't say I am feeling fed up, can someone come around have a cup of coffee for an hour"* (Middleton, 1998, p.243). These parents were discussing social workers, but Middleton excluded families currently involved in investigations, so respondents probably represented families who were most likely to perceive they had some influence. Similarly, when their children with LD were admitted to a Paediatric Intensive Care Unit (PICU), parents found themselves excluded from care processes: *"..I mean I try to help and sometimes I do and sometimes I am told well very kindly just to step aside, which I do. I do not argue with that but we are expected to be the experts at home.."* (Graham et al. 2009, p2066). Parents were aware when they failed to abide by the established power order: *"We were taking control rather than the professional taking control, ... But telling them what you want, it's a role reversal"* (Todd & Jones, 2003, p236).

Only three of the 18 papers discussing power dynamics referred to them positively and in one study, parents' perception of inequality had led to a breakdown in PPPs: *"There's no support. You must do things their way. You've got no choice"* (Swain & Walker, 2005, p553). Parents' felt angry, distrustful and thought they had to be on their guard (Lindblad et al. 2005). These parents received intensive, long-term support from professionals at home, which might make their situation different from other respondents. However, other interviews were scattered with references to *'struggling'* and *'fighting'*. Professionals could be described pejoratively in the third person plural, implying that parents felt negatively about their interactions with them: *"..They think you don't know what you are doing and it's their job to tell you"* (Todd & Jones, 2003, p237). A frequent discussion point was how parents' felt assessed, scrutinised and judged in the partnership (Avdi et al. 2000): *"It's like letting your guard down in front of other people...you become vulnerable and are judged"* (Brett, 2004, p16).

Parents varied in how they responded to inequality. Some appeared passive: *"You learn you can't have everything you want from them (professionals). You take what's best from what's on offer"* (Todd & Jones, 2003, p240). Others fought: *"I don't listen to a word doctors say anymore. In fact I'll do the opposite..."* (Todd & Jones, 2003, p235) or used strategies to protect themselves and their child. For instance, some sought support elsewhere (Lindblad et al. 2005). Additionally, some mother's described trying to present themselves to professionals as stereotypically 'good' mothers, to deflect negative judgements (Todd & Jones, 2003).

Professionals

Professionals rarely explicitly acknowledged the power they had and infrequently talked positively about sharing power with parents. For example, although professionals in Lindblad et al's. (2005b) paper were humble of parents' knowledge and experience and thought parents brought equal qualifications to the partnership, they considered that they carried the main responsibility for the partnership. They thought their role included informing parents of their legal rights and advising them how to correspond with other professionals. They also perceived a role in standing up to bureaucratic rules and unhelpful colleagues. This can be construed as paternalistic. These professionals had been chosen by families because they were judged to be supportive. This validates the opinions expressed as informative of good practice and suggests that inequality can sometimes be worked with positively.

Although not openly acknowledged, it seemed difficult for professionals to relinquish power. Some acted defensively if their power was alluded to: *"You know parents of these children have had a devastating experience.... Some parents need to fight you know"* (Swain & Walker, p558). Others indicated mixed responses when they acquiesced to families' decisions: *"because they can't foresee the consequences of their actions...."* (Minke & Scott, 1995, p346). Sometimes they gave the impression that they felt manipulated by parents who were construed as powerful. For example, Middleton's (1998) social workers believed parents could exaggerate their child's disability to secure sympathy and help. Minke and Scott (1995) found that, of 109 statements about families' partnership abilities, only 19 were optimistic. Sixteen were sympathetic to parents and 74 focused on things that would reduce the likelihood of parent participation. The authors noted that staff had middle Socio-Economic Status (SES), whereas, parents had lower SES and status differences might therefore influence PPPs. Even in Watson et al's relatively recent (2006) paper, professionals, who ranged in experience from two-to-20 years, varied in how much they believed parents should be their child's therapist, and therefore share power.

Ferguson (2008) reviewed correspondence between parents and a superintendent who oversaw care, admissions and discharges at an American institution between 1908 and 1930. He summarised that PPPs have changed relatively little: *"Perhaps it is inevitable: an awkward dance between partners each doubting the other's capacity to lead but tied together in an unavoidable push and pull..."* (Ferguson, 2008, p57). Similarly, Avdi et al. (2000) concluded that the dilemma between authority and equality can not be resolved in partnership. This has serious implications because as a parent exclaimed: *"If we feel powerless, can you imagine how powerless our children feel"* (Freedman & Boyer, 2000, p62).

Two other topics sometimes discussed were empowerment and advocacy. Although closely related to negotiating power dynamics, these are described as sub-topics because they formed distinct discussion points.

Empowerment

Professionals in Lindblad et al's. (2005b) paper talked about empowering parents and they encouraged and confirmed parents' decisions and listened to and requested parents' opinions and desires. However, empowerment requires mutual agreement and there can be mismatched perceptions of what is wanted. For example, parents' preferred pro-active services but social workers worried parents would view this as intrusive and interfering (Middleton, 1998). Parents rarely talked about being empowered by partnership and some parents said professionals could leave them doubting their competence: *"I felt totally inadequate, really, and I was made to feel that by these health professionals"* (Todd & Jones, 2003, p234).

Advocacy

Advocacy can be defined as speaking for or on behalf of a person or cause (Gray et al. 2009). Some professionals saw advocacy as critical: *"it doesn't have a huge effect if you can't empower the parents to be able to advocate for their child"* (Minke & Scott, 1995, p341). Sometimes parents embraced advocacy. Watson et al's. (2006) parents' perceived their role to include advocacy and several of the mothers in Todd and Jones' (2003) study said they were '*fighters*' for their children. As one mother said: *"I don't think anything will happen without a fight"* (Todd & Jones, 2003, p232). However, timing influenced when this role was assumed. Parents were not always ready to participate: *"...for the first year or two I needed direction... I don't think I was ready to participate in anything,.."* (James & Chard, 2010, p.280). Gradually parents started to speak up: *"I've actually got* *to the stage now where I can say...just communicate with me and make sure that I understand"* (James & Chard, 2010, p281). Similarly, over time the mothers in Todd and Jones' (2003) study moved from passivity to being able to challenge professionals. However, parents in Fereday et al's. (2010) study remained concerned that professionals would view them as being *"pushy"*.

Interpersonal factors

Parents

Many parents reflected on professionals' personal attributes. For instance, 43% of respondents in Knox et al's. (2000) study said it was important that professionals were welcoming and friendly and 40% that they were good communicators. Parents often tested professionals for these attributes by asking questions to evaluate their knowledge and attitudes (Watson et al. 2006). First encounters with professionals, when parents must confront their child's disability, can have long-term effects on PPPs (Todd & Jones, 2003). Parents' cited a lack of sensitivity and the period of diagnosis was described as offering little empathy and Avis and Reardon's (2008) parents expressed similar views.

Positive interpersonal factors

Parents found it helpful when professionals were easily accessible, aware of the situation, listened to them and responded (Lindblad et al. 2005a, Swain & Walker, 2005). Similarly, parents in Dunst et al's. (1988) study had a greater sense of control if professionals were friendly, honest, sincere and respectful. Parents in Freedman and Boyer's (2000) paper said their critical support was someone who listened.

Parents sometimes mentioned bonding as an element in PPPs: *"They were very caring...our whole experience after that point was a bonding one"* (Minke & Scott, 1995, p343). Parents in Fereday et al's. (2010) study similarly talked about establishing trust. As a parent said: *"they're in your life, and they're such a big part of your life two days a week that it's hard to keep that parent-therapist relationship strictly that way.."* (Watson et al. 2006, p656). Parents said professional roles included those of *"friend"*, *"family"* and *"mother"* (Lindblad et al. 2005a). Fox et al. (1997) explored a family's perceptions of a positive behaviour support intervention. The mother attributed the success of the programme partly to her emotional connection with the interventionist. As this professional was the second researcher, this bond may have biased the mothers' reports. This mother had actively sought help and she was a parent consultant with an early intervention service, which compounded the bias because the family seemed to have been selected because they had a good relationship with services.

Negative interpersonal factors

Parents said being treated as individuals was the foundation of a trusting relationship so being rejected as an individual was painful, especially at vulnerable times, such as at diagnosis: *"He just sat there and nothing, but I mean not even a little pat on the shoulder or something. He didn't ask if I wanted to talk to someone...he didn't ask how things were for me.....or if I had anyone"* (Lindblad et al. 2005, p.290). Similarly the mothers in Todd and Jones (2003) study talked of being upset when they were treated as non-persons and their feelings were discarded.

Negative PPPs were often described in terms of interpersonal aspects and in Knox et al's. (2000) study thirty-six percent of parents said professionals who lacked sensitivity could inhibit partnership. Mothers in Todd and Jones' (2003) study thought contact with professionals was judgemental, disempowering and increased anxiety. The time needed to build trust with professionals was lacking (Fereday et al. 2010): *"There's an awful lot of inconsistency with people, I think. No sooner do you build up a relationship... and then that person moves on"* (Todd & Jones, 2003, p238), although for some a change of professionals could introduce new perspectives (James & Chard, 2010). Power dynamics impacted on interpersonal interactions as parents often knew little about professionals' personal lives. For some this was acceptable, but for others it was a concern: *"They just become involved in your life... we're not really involved in theirs, you know...they know every detail of our life..."* (Watson et al. 2006, p656).

Professionals

Professionals discussed the interpersonal aspects of partnership less. Staff in Lindblad et al's. (2005b) study said mutual trust was essential. They talked about being authentic and honest and showed loyalty by being a constant partner. However, in Minke and Scott's (1995) study, staff expressed mixed views about becoming part of a family system: *"...and people will become dependent on you and you won't know how to undo that..."* (Minke & Scott, 1995, p344).

Emotional Support

Parents

Many parents said partnerships did not meet their emotional needs, which is unfortunate as Brett's (2004) parents indicated that deciding to accept support was associated with feelings of anxiety and distress. Parents in Hall's (1996) study acknowledged their fighting spirit but thought community nurses' assumed they could cope. Similarly, parents in Middleton's (1998) paper found that services concentrated on physical rather than emotional issues. Support was particularly lacking at critical times, such as at diagnosis (Hall, 1996), when reassurance and support were needed (James & Chard, 2010).

To discuss their feelings, parents must bring their own needs into the partnership. This seems to be a challenge for parents. For example, one mother commented: *"I don't want to be pitied because I have this child with a disability"* (Fox et al. 1997, p202). Yet some parents did tentatively raise their own needs: *"I have sort of made prompts….. "* (Todd & Jones, 2003, p239) and others reportedly made clear demands (Lindblad et al. 2005). Avis and Reardon (2008) suggested cultural practices may influence what form of emotional support is wanted. However, in other papers reticence seemed to relate to power dynamics. Parents' felt that their own needs were not legitimate and might cause professionals to perceive them as selfish, thus undermining their struggle to be seen as advocates. One mother said that it was best to remain silent about issues that called into question her status as a good mother and this was endorsed by another mother who said getting professionals to view her as a good mother was a struggle, so she avoided talking about herself. This topic is summarised in the quotation: *"What are you going to do for me? I'd be a right selfish cow wouldn't I?... you're not going to get into that situation with them. But it would be nice if some asked like, 'what about you Mrs Grundy, what can we do for you now'"* (Todd & Jones, 2003, p240).

Parents sometimes talked about the partnership itself in emotional terms. If they were ignored they felt *'sad', 'angry', 'powerless', 'devalued'* and *'inferior'* and there was a sense that they were being attacked when they were defenceless. If their worries were not eased they felt *'drained', 'exhausted', 'uncertain' and 'frustrated'* (Lindblad et al. 2005).

Professionals

Some professionals were aware of parents' emotional needs, but instead of addressing these they used strategies of normalizing the emotions and affirming the persons' parenting, because a constant emphasis on problems was thought to be disconfirming (Watson et al. 2006). Social workers in Middleton's (1998) study were divided about whether they could meet parents' emotional needs, as they were unsure if these required professional counselling.

Consideration of the child

Parents

Parents thought consideration for their child was often lacking and frequently sought clues about how professionals viewed their child (Watson et al. 2006). Parents felt sad and confused if professionals acted as if their child had limited potential and focused on the disability: *"It's really one-sided. Who is going to deal with that, with the positive things?"* (Lindblad et al. 2005, p293). Similarly, mothers in Larson's (1998) study recounted how some doctors did not appreciate and respect their child as unique and parents' with children on a PICU spoke of how their child's abilities were often under-estimated: *"..They (the PICU) really do not know her. How do you get them to know her"* (Graham et al. 2009, p2066). There were two interviewers in this study, one of whom was a parent of a child with a LD. However, the other interviewer had previously cared for one of the children during an admission, meaning some parents might have been reticent in voicing their opinions.

To protect their child from unworthiness parents' spoke their mind, questioned, demanded change and showed their feelings regardless of professionals' reactions (Lindblad et al. 2005). Professionals who showed a personal interest in the child were perceived as believing the child was unique and worthy (Watson et al. 2006): *"I mean it's nice when your child receives attention first"* (Lindblad et al. 2005, p293). Parents in these situations felt pleasure, delight and trust. Professionals helped parents to see their child's potential and abilities and helped them understand the child's development. Parents expressed trust, security and gratitude when professionals perceived the child's emotions and practical needs and did everything they could to meet them (Lindblad et al. 2005).

Professionals

Although, staff in Lindblad et al's. (2005b) study perceived that parents' trusted them more when they saw that their child was appreciated, the importance of the child was scarcely evident in professional narratives.

Children

How children contribute to PPPs has received little attention. In their study, Swain and Walker (2005) acknowledged that they did not include children, as only two parents consented to their children's involvement. They concluded that when parents and professionals disagree, children's views are not considered.

Garth et al. (2009) explored ten children with cerebral palsy's contribution to partnerships. Parents and doctors were also interviewed and unfortunately the themes were not examined separately for each respondent triad. PPPs normally started didactically, as younger children were less interested in partnership, and then became a triad as children became more able to participate. It was important that children were listened to and included and that the doctor gave them explanations. Doctors often adopted strategies to encourage children's involvement and when children engaged willingly in partnership they enjoyed the experience, felt involved and important. However, adults controlled children's involvement in discussions and decisions and sometimes withheld information from them.

Discussion:

Summary

This review of qualitative studies addressing PPPs when children have LD suggests that the key ingredients of effective partnerships are: a) professionals using interpersonal skills to negotiate power dynamics, to empower parents and enable them to advocate for their child and b) professionals attending to parents' and children's emotional needs. Table three, illustrates how these topics match the partnership attributes identified by Bidmead and Cowley (2005) with the exception of 'consideration of the child'. This small discrepancy may be explained by the differences between PPP in routine health visiting and the more extensive partnerships that evolve when children have LD. Information giving was a less prominent topic and has not been discussed separately in this paper, because of the focus on interpersonal aspects of PPPs. This consistency in topics provides some validity for the review findings and suggests that several features of partnership are stable across different service contexts (Table 4).

Clinical Implications

Recruiters for professional training and posts need to be able to discern which people have the necessary interpersonal attributes to work alongside families. However, professionals may need additional training to provide aspects of this approach, such as how to recognise and negotiate power dynamics. It remains contentious whether the FCC approach to working with families can be 'taught', but this debate is beyond the scope of this review. Figure four provides a tentative model of the components of effective PPPs based on the literature review. (Figure 4). Figure four was informed by the framework approach step of mapping and interpretation, where the data collected is interpreted as a whole and summarised into a useable format. The model presents partnership as a triadic relationship, incorporating the ideas summarised in the 'Respecting the child' theme. The model includes all the themes discussed as key ingredients and highlights how these elements of partnership can be influenced by the parent, child and professional. However, empowerment and advocacy roles are assigned primarily to professionals, as this reflects how professionals included in this review said they contributed to partnerships. The model places partnership in the organisational context and acknowledges that parents often gain support from other sources as well as PPPs.

By placing partnership in the organisational context the proposed model incorporates the idea that professionals need the support of the service to form effective partnerships. How the organisation influences professionals' partnership behaviours is seldom considered. Partnerships must be modelled in organisations' structures, cultures and working relationships. In the context of child protection, Morrison (1996) stated that services' failure to contain anxiety made it difficult for staff to relinquish paternalistic practices. A further clinical implication is that professionals need to be flexible when deciding how to work with a particular family. This is discussed below in relation to the literatures' limitations.

Review limitations

There are some caveats about the strength of the evidence available to support the proposed model. The review included a range of papers and it was sometimes unclear whether all the children referred to had a LD. The large age range in some of the papers included adults as well as children. These papers were included as this was an initial attempt to synthesise the literature and these papers contributed information about important aspects of partnership. However, in future reviews a stricter selection criteria might enable clearer conclusions about PPP in child LD services.

There are also fewer reports on professionals' views of PPPs, but generally their discourses corroborate the topics evident in parents' narratives. Additionally, this review was not exhaustive and some papers were not obtained. The adapted use of the CASP tool to judge the quality of papers was helpful, but ratings depended on personal judgement about whether a criterion had been fulfilled. Therefore there was only 90% item-by-item agreement between the two raters, with middle rating papers being the most difficult to judge against the criteria. It is also acknowledged that information from different qualitative methodologies have been collated, though the different methodologies will have impacted on what findings were reported.

Literature limitations

There remains an assumption that all families with children with LD have similar needs, resources and circumstances (Dale, 1992). However, the samples included in this review were heterogeneous. Not every parent wants partnership and sometimes other approaches to working with families are more appropriate (Gabe et al. 2004). Two factors that might create this variability are developmental factors and the extent of the child's LD: children with mild LD are often overlooked (Einfield & Tonge, 1996) and research on PPPs needs to pay greater attention to lifespan concerns and transition points (Todd & Jones, 2003). Additionally, cultural practices might impact on PPP's (Avis & Reardon, 2008).

There are voices absent from the literature that might add further variability to critiques of PPPs. Fathers' opinions are under-represented (Hall, 1996) and when they contribute their views are not discussed separately from mothers' opinions. The views of children are also absent. As well as an ethical concern, the lack of children's perspectives makes it difficult to understand partnerships, because exploring dyads does not reveal triadic behaviours (Tates & Meeuwesen, 2001). Future research also needs to consider the benefits of PPPs, as only five papers considered outcomes.

Conclusions

The literature endorses PPP as a critical element of providing FCC. The message from the research is that negative PPPs are not inevitable (Case, 2001) and the literature suggests how they can be improved (Hodge & Runswick-Cole, 2008). Drawing on the qualitative literature, this paper has proposed a tentative model of the components of effective PPPs when children have LD. Yet several interesting issues have yet to be explored, such as how PPPs are influenced by an organisations culture and the child's developmental stage. To further our understanding of PPPs it is crucial that children's opinions are included.

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Tables:

Table One: Bidmead & Cowley's, (2005) attributes of partnership

1. A genuine and trusting relationship
2. Honest and open communication and listening
3. Praise and encouragement
4. Reciprocity
5. Empathy
6. Sharing and respect for the others expertise
7. Working together with negotiation of goals, plans and boundaries
8. Participation and involvement
9. Support and advocacy
10. Information giving
11. Enabling choice and equity

Table Two: Papers included in the literature review.

Authors	**Year**	**Participants**	**Children's age and diagnosis**	**Purpose**	**Method**	*Authors core themes* **Key Topics**	**Critical Appraisal Skills Programme Rating**
Parent and professionals							
James & Chard	2010	4 mothers 3 couples	Pre-school Cerebral palsy, spina bifida	To explore perceptions of an early intervention service	Semi-structured interviews analysed using Interpretative phenomenological analysis	*The early years: a new experience* *Empowerment: now I'm ready* *Collaboration: the middle ground* **Empowerment** **Advocacy** **Interpersonal factors**	9/10
Garth et al	2009	14 Parents 9 Paediatricans	8-12 years Cerebral palsy	To explore how children contribute to partnerships	Interviews analysed using grounded theory	*Creating a space for the child's involvement* *Acknowledging variability of child preference* *Negotiating child's age and development* **Consideration of the child**	9/10
Ferguson	2008	100 case files	Unspecified	To explore partnerships in the early twentieth century	Document analysis incorporating discourse analysis	*Negotiating custody* **Negotiating power dynamics** **Emotional support**	7/10
Watson et al	2006	15 mothers 5 fathers 1 nurse 2 social workers 4 occupational therapists 3 physical therapists 4 speech pathologists	15 months- 14 years Cerebral palsy, retardation, spina bifida	To explore partnerships in early intervention	Interviews analysed using grounded theory	*Striving for therapeutic relationships* *Strategies for striving for therapeutic relationships* **Negotiating power dynamics** **Advocacy** **Interpersonal factors** **Emotional support** **Consideration of the child**	10/10
Parent perspectives							
Fereday et al	2010	28 parents 3 grandparents 3 foster parents	Unspecified (most under 10 years)	To explore families experiences with general health care professionals	Semi-structured interviews and focus groups analysed using a	*GHP-parent partnerships* **Negotiating power dynamics** **Advocacy** **Interpersonal factors**	8/10

				(GHP)	thematic approach	**Emotional support** **Consideration of the child**	
Graham et al	2009	8 parents	1.7-20.4 years Chromosomal abnormalities Multiple anomalies Tuberous Sclerosis Severe LD and spastic quadriplegia, Epilepsy Epilepsy + chronic pain Spinal muscular atrophy Mytonia + multiple congenital anomalies	To explore perspectives of families' whose child with severe disabilities was admitted to Pediatric Intensive Care	Semi-structured interviews analysed using open and axial coding of themes.	*Know the child's baseline* *Integrate and bridge multiple services* *Disconnection between role of parent at home vs parent in PICU* *PICU admission doesn't equate with respite* *High stakes learning environment* *Hetrogenity within group* *Lack of fit with acute care model* **Negotiating power dynamics** **Advocacy** **Consideration of the child**	8/10
Avis & Reardon	2008	12 parents	Unspecified	To explore families experiences of nursing care	Semi-structured interviews analysed using thematic approach	*Prior experience of hospital care* *Communication support* *Nurse-parent relationships* *Parents perceptions of nurses and nursing* **Negotiating power dynamics** **Interpersonal factors** **Emotional support** **Consideration of the child**	8/10
Lindbald et al	2005	10 mothers 6 fathers	2-16 years Physical and learning disabilities, learning disabilities, physical disabilities	To explore experiences of being supported by professionals	Interviews analysed using phenomenological hermeneutic approach	*Gaining confidence as a parent and being obstructed from gaining confidence as parent* *The chid is acknowledged as valuable and the child is not acknowledged as valuable* **Negotiating power dynamics** **Interpersonal factors** **Emotional support** **Consideration of the child**	9/10
Swain & Walker	2005	12 parents (5 interviewed)	Unspecified	To explore experiences of a	Open-ended questionnaire items	*On the centre* *On relationships between centre and services*	7/10

				parent devised conductive education centre and local services	and semi-structured interviews analysed using grounded theory	**Negotiating power dynamics** **Consideration of the child**	
Brett	2004	6 parents	Unspecified	To explore parents experience of support	Interviews analysed using hemeneutical phenomenological approach	*Parents feelings about support* *Journey to accepting support* *Support as a loss* *Disability and the parent* *The supportive relationship* **Negotiating power dynamics** **Emotional support**	6/10
Todd & Jones	2003	30 mothers	11-19 years Intellectual disabilities	To explore how parents relate to professionals	Semi-structured interviews analysed using grounded theory	*Good mums and bad professionals* *Muted voices* *Fighting talk: subsequent professional relationships* *Disciplined advocates* **Negotiating power dynamics** **Empowerment** **Advocacy** **Emotional support**	7/10
Avdi et al	2000	3 mothers 2 fathers	2.5- 3 years Developmental delay, mild autism, autistic tendencies	To explore constructions of professionals during autism assessments	Interviews analysed using discourse analysis	*No theme titles* **Negotiating power dynamics**	9/10
Knox et al	2000	68 mothers 14 fathers 1 grand-parent	<3- >19 years 6 Autism, intellectual disabilities, behaviour difficulties, physical disabilities, multiple disabilities	To explore the significance of perceptions of control in partnership	Interviews analysed using content analysis and percentage agreements	*Having positive prospects for the family's future* *Genuine sharing of decision making with service providers* *The ready availability of pertinent information* **Negotiating power dynamics** **Interpersonal factors**	7/10
Freedman & Boyer	2000	21 mothers 8 fathers 2 partners	2-37 years Downs syndrome, developmental	To explore perceptions of the American flexible	Two focus groups analysed for key themes	*Types of family support* *Effects and flexibility of family supports* *Barriers*	8/10

			delay, cerebral palsy, multiple medical conditions, autism, retardation	payments scheme		*Unmet needs* **Negotiating power dynamics** **Interpersonal factors** **Emotional support**	
Larson	1998	6 mothers	5- 11 years Cerebral palsy, spastic quadrapesis, blind and global developmental delay, high functioning autism	To explore experiences of parenting a child with LD	Case studies- including interviews analysed thematically	*Acceptance and denial* *Definitive diagnosis vs embrace of paradox* *Predictions for the trajectory of care* *Positive illusions and the embrace of paradox* **Emotional support** **Consideration of the child**	7/10
Middleton	1998	9 parents	Disabled- no other information	To explore views of social work services	Interviews analysed thematically	*Nature of valued social work support* *Means of access to social services* **Negotiating power dynamics** **Emotional support**	7/10
Fox et al	1997	Mother Father Brother	9 year old with Cornelia DeLange syndrome	To explore reflections on an positive behaviour support intervention	Semi-structured interviews and audio-journal. Analysed using constant comparative method.	*Impact of problem behaviour on the family* *Impact of positive behavioural support* **Negotiating power dynamics** **Advocacy** **Interpersonal factors** **Emotional support** **Consideration of the child**	8/10
Hall	1996	4 parents	3- 19 years Statement with special educational needs	To explore perspectives of community nursing service	Interviews analysed for frequency of themes.	*No theme titles* **Negotiating power dynamics** **Emotional support**	7/10
Minke & Scott	1995	7 mothers 1 foster mother 1 grand-mother	0- 3 years Environmental risk of developmental delay, mild language delay, multiple delays, developmental delay, global developmental	To explore the introduction of individual family service plans	Videos of meetings and semi-structured interviews were main sources analysed using grounded theory	*Personal parent-staff relationships in encouraging active participation* *Staff reactions to parent participation* *Problems with the individual family service plan process* **Interpersonal factors**	6/10

			delay, multiple disabilities				
Dunst et al	1988	2 couples	3.5- 4 years Degenerative autosominal recessive disorder, microencephalic spastic quadriplegia and epilepsy	To explore unhelpful and helpful professionals and their impact on sense of control	Interviews analysed by matched themes to their conceptual framework	*Pre-helping attitudes and beliefs* *Helping behaviours* *Post-helping responses and consequences* *Behaviour outcomes* **Negotiating power dynamics** **Interpersonal factors**	6/10
Professional perspectives							
Lindblad et al	2005	1 occupational therapist 1 SEN teacher 1 paediatric nurse 2 paediatricians 1 personal assistant 1 person in charge of legislative rights 2 children's nurses	2-16 years Severe learning disabilities	To explore experiences of being a supporter	Interviews analysed using phenomenological hermeneutic approach	*Being grounded in a personal and professional philosophy about the task* *Being confident that it is always possible to help* *Being a trustworthy partner* *Enabling parent sot gain competence and confidence in parenthood* **Negotiating power dynamics** **Empowerment** **Interpersonal factors** **Consideration of the child**	9/10
Swain & Walker	2005	6 centre staff 6 consultants 5 physiotherapists 4 speech and language therapists 1 health staff 1 occupational therapist 1 social worker 1 educational psychologist	As described above	As described above	As described above	**Negotiating power dynamics**	7/10

		1 education staff					
Middleton	1998	32 social workers	As described above	To gain their opinions of parents' comments about the service	As described above	**Negotiating power dynamics** **Emotional support**	7/10
Minke & Scott	1995	4 administrators 10 direct service staff	As described above	To explore the introduction of individual family service plans	As described above	**Negotiating power dynamics** **Empowerment** **Interpersonal factors**	6/10

Table Three: Main topics identified

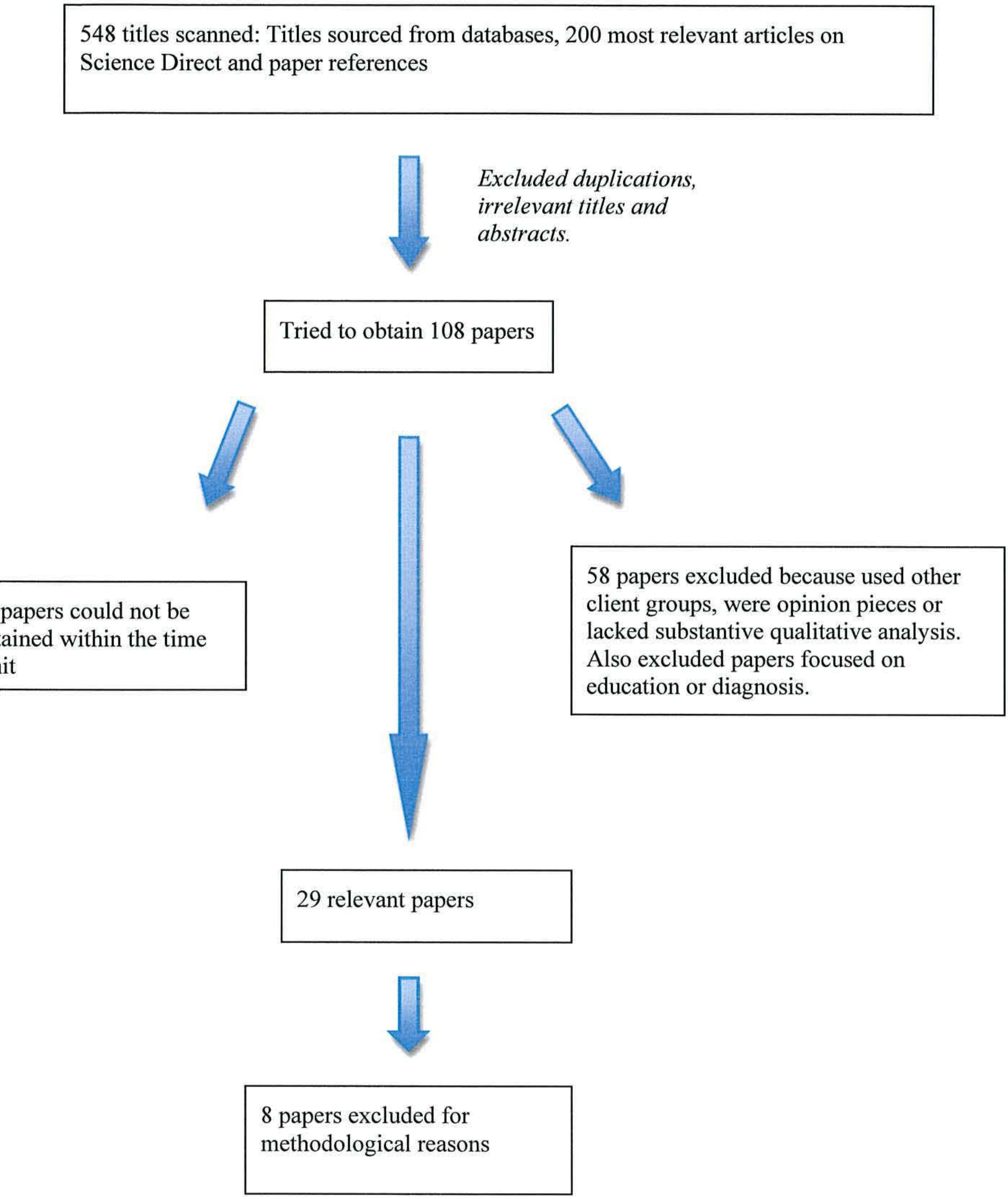
Topics	Number of papers discussed in
Power dynamics	18
Subtopic: Empowerment	4
Subtopic: Advocacy	6
Interpersonal factors	11
Emotional Support	13
Consideration for the child	10

Table Four: How the identified topics match Bidmead & Cowley's, (2005) attributes of partnership

Bidemead & Cowley	Prevalent topics
Genuine and trusting relationships Honest and open communication and listening Praise and encouragement	Interpersonal factors
Information giving	Some comments related to this occurred in interpersonal factors
Reciprocity Sharing and respect for other's expertise Working together with negotiation of goals, plans and boundaries Enabling choice and equity	Negotiating power dynamics
Empathy	Emotional needs
Participation and involvement Support and advocacy	Advocacy and Empowerment

Figures:

Figure 1: Literature Search



548 titles scanned: Titles sourced from databases, 200 most relevant articles on Science Direct and paper references

Excluded duplications, irrelevant titles and abstracts.

Tried to obtain 108 papers

papers could not be
ained within the time
it

58 papers excluded because used other client groups, were opinion pieces or lacked substantive qualitative analysis. Also excluded papers focused on education or diagnosis.

29 relevant papers

8 papers excluded for methodological reasons

Figure 2: Pie chart to show the range of respondents (by percentage)

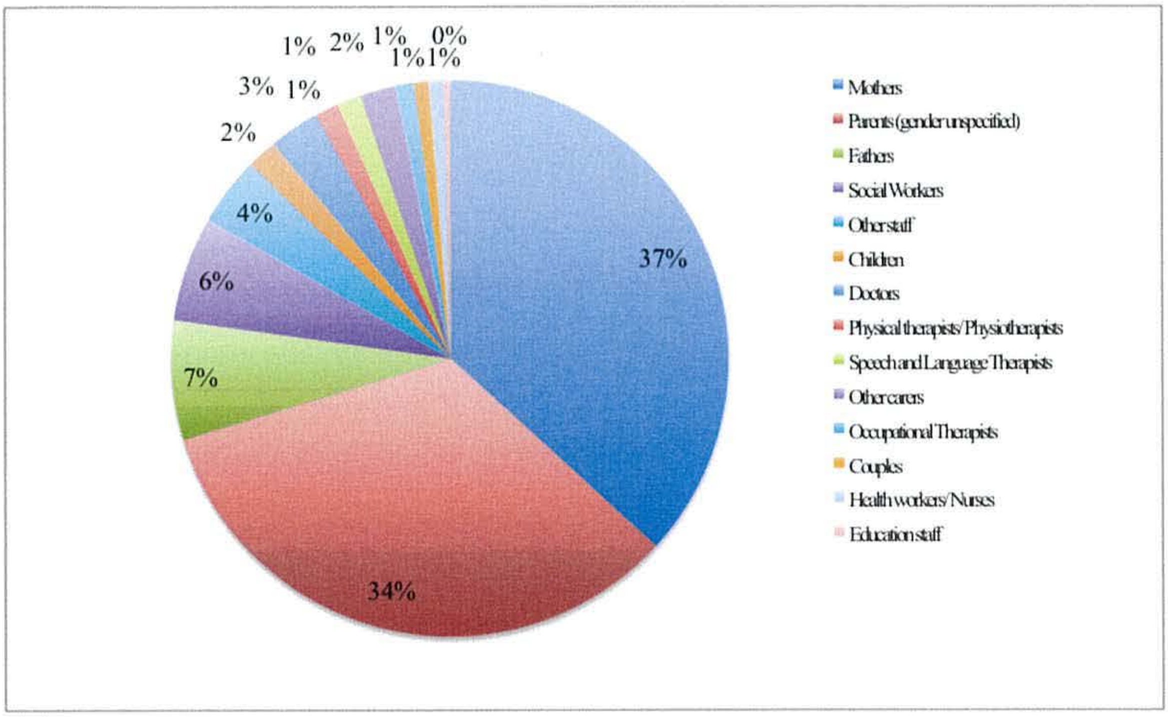


Figure 3: Pie chart of the child diagnoses included in the review
(summarised as the percentage of papers including each diagnosis)

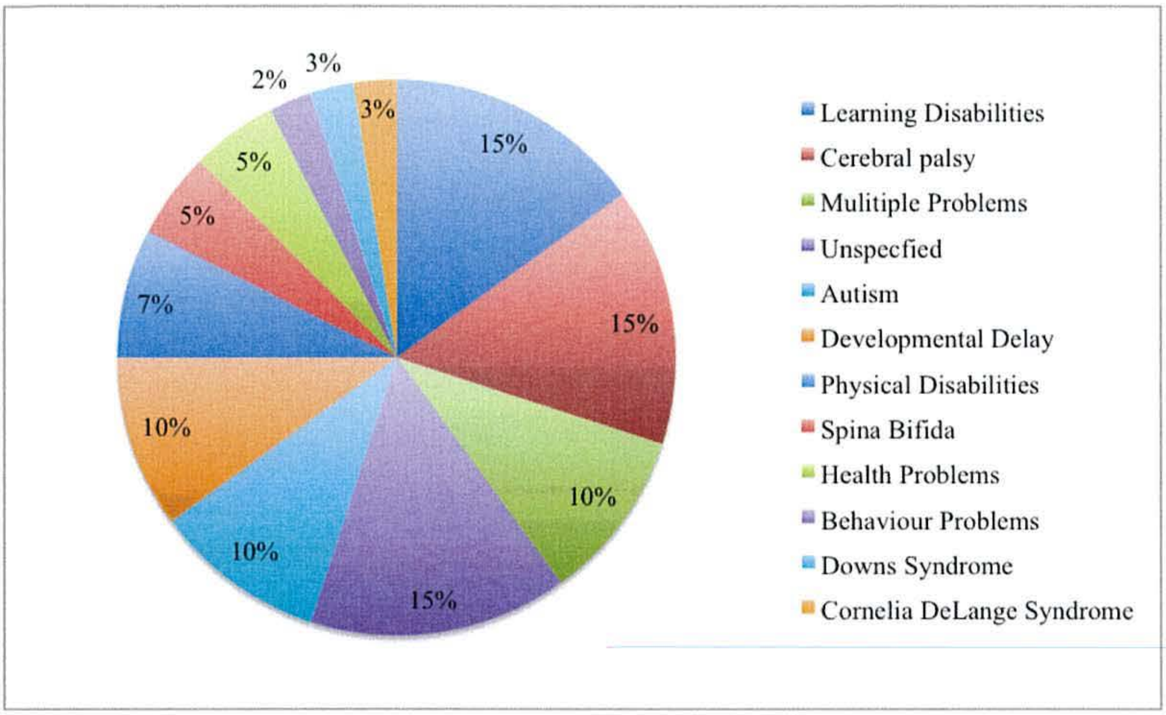
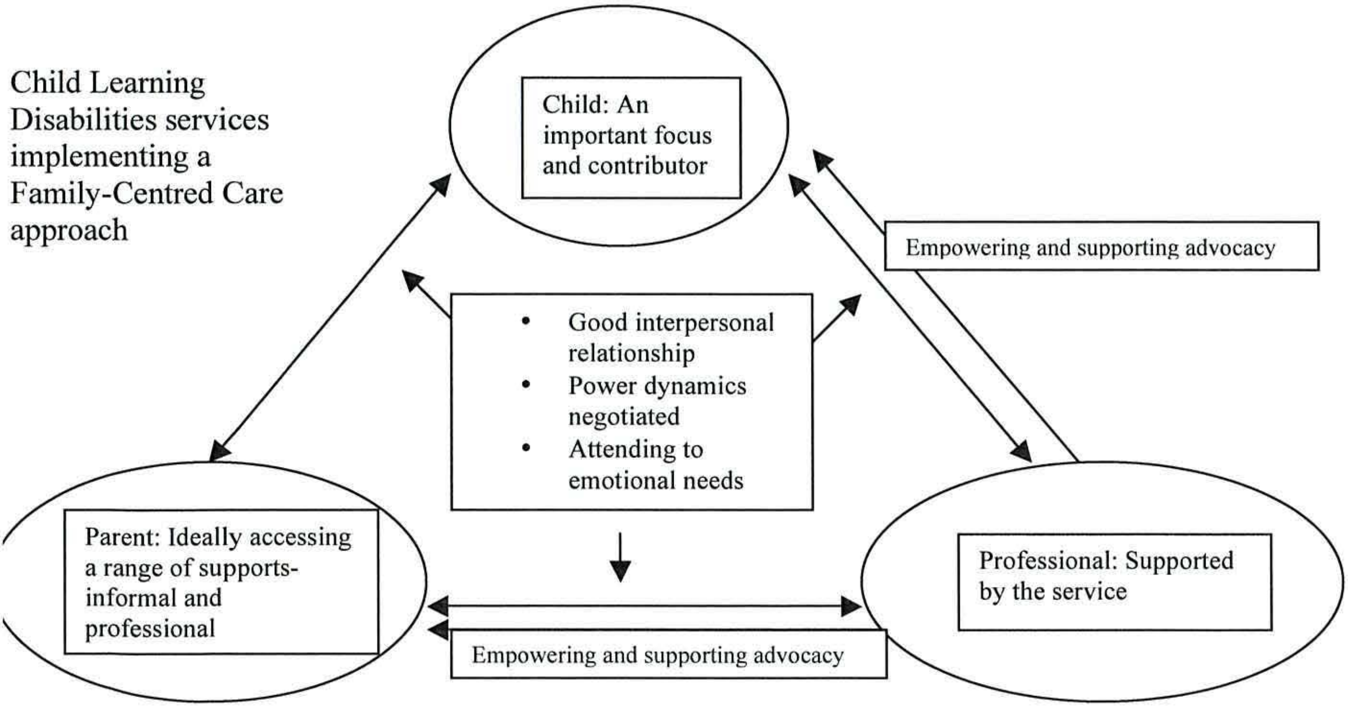


Figure 4: Model of effective PPPs in child LD services



Key Messages:

- Four main topics are evident in the studies
- Negotiating power dynamics remains a central concern in PPPs
- Negative PPPs are no longer inevitable
- Research lacks the perspectives of fathers and children
- Research needs to focus on triadic relationships

Empirical Paper A

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Service use amongst UK families: what impact does child learning disability have?

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Abstract 148

Background: Parents of children with learning disability (LD) often experience psychosocial burdens and may benefit from professional support. However, there is limited information about how frequently these families access services or about what predicts their service contact.

Materials and Methods: The Office of National Statistics 2004 dataset (N;7977) explored mental health amongst children in the United Kingdom. A secondary analysis was conducted about the extent and correlates of service access in families with a child with LD. These families were compared to families where the child had psychiatric disorder, LD and psychiatric disorder or was typically developing.

Results and conclusions: Children with LD accessed few services but those with psychiatric diagnosis accessed mental health services at similar rates to children with just psychiatric diagnosis. The main correlates of service use were gender, psychiatric diagnosis, LD and maternal emotional disorder. Families' perceptions of services now need to be explored.

Introduction

Family-Centred Care (FCC) states that parents and professionals should work collaboratively with mutual respect. This approach is proposed to be important in engaging families with services (Dunst et al. 2002), especially when children have difficulties, such as learning disability (LD), which can increase families' social and psychological burdens (Bella & Mahoney, 1998). However, before investigating how the FCC approach influences service engagement, it is necessary to consider what contact children with LD have with services.

Service contact

There have been few attempts to characterise children with LD's service contact. Newacheck et al. (1998) presented data from a representative sample of the American children. They found that six percent of children with chronic physical, developmental, behavioural or emotional conditions did not have increased contact with health and related services as expected. Benedict (2006) considered just the use of therapeutic services such as, occupational therapy. In a sample of 3,434 American children with functional limitations, including LD, she found that 15% had unmet service needs. Two correlates of service contact were family education level and finances.

The use of mental health services has also been investigated. Witt et al. (2003) presented data from the American National Health Interview Survey. Children were aged 6-17 years and the definition of disability employed incorporated children with health and physical difficulties. Only 14.3% of these children had accessed mental health services in the previous year. Children with functional impairments in communication, social or learning behaviour, families with publicly funded insurance and families with greater financial burden were more likely to have had contact. There was less service access when professionals were not involved in coordinating care. Further research has explored children with LD and concomitant psychiatric problems (dual diagnosis) use of mental health services.

Dual diagnosis

Experimental studies have suggested that professionals diagnose psychiatric problems in people with LD less frequently because psychiatric problems are less salient and perceived as less significant. For instance, children may not be referred because families are not concerned about their symptoms (Cooper et al. 2011). In a typical study, Mason and Scior (2004) found that clinical psychologists and psychiatrists assigned a psychiatric diagnosis less frequently when the vignette they were given indicated the person had an IQ of 58 (compared to 108). However, as they commented using vignettes oversimplifies the decision making process and cannot fully model clinical decision making.

In terms of service use data, the evidence for diagnostic overshadowing is mixed. Using a subset of participants from a longitudinal study, Floyd and Gallagher (1997) found limited use of specialist services. However, children who had concomitant behaviour problems accessed more mental health services. Parents with children with LD reported high levels of pessimism, and the researchers' hypothesised that this led them to 'give up' seeking support. More recently, Dura-Vila and Hodes (2009) reviewed the case notes of 242 children from ethnic minorities living in London, aged

7-17 years with mild-to-moderate LD. Forty-three children were using Child and Adolescent Mental Health Services (CAMHS). Family composition significantly predicted service use: 11.5% of two parent families used CAMHS compared to 24.6% of single or foster families. Unfortunately, actual service use was not verified and the frequency and duration of support was not investigated.

In an unpublished report, Emerson and Hatton (2007b) using data from the Office of National Statistics (ONS: Green et al. 2005), compared children with psychiatric diagnosis to children with LD and a psychiatric diagnosis. There was a trend for children with LD and psychiatric problems to access more services, and 'hard pressed' families tended to have less contact with services. Factors influencing contact varied across services. In CAMHS, older children, girls, families' functioning less well and mothers' with good mental and general health had less contact. However, they combined access data with parental judgements of helpfulness and as only children with psychiatric diagnosis with and without LD were explored, it is unclear whether these factors are general features amongst families who access services. Additionally, although use of individual services was explored, it would be interesting to compare different groups of services, e.g. those that need a referral compared to primary care and specialist mental health services.

Study aims

This secondary data analysis considered the extent of service access and correlates of service contact amongst children with Learning Disability (LD) with and without psychiatric diagnosis. In 1999 and 2004 the ONS surveyed the mental health of children and adolescents in the UK. The ONS dataset is an unbiased, UK-representative sample, although 82 addresses without postcodes and families whom the child benefit centre were taking action against were excluded and 631 families could not be traced. A methodological strength of this survey was that psychiatric problems were diagnosed on the basis of clinical information, so pre-existing diagnoses did not affect the likelihood of participation.

Using the ONS (2004) survey this secondary analysis aimed to:

(a) Explore service contact among children with LD, controlling for psychiatric diagnosis: The service contact of four comparison groups was explored (children 'typically developing', 'with LD', 'with psychiatric diagnosis' and 'with dual diagnosis'). Additionally, the use of different types of services was compared. This extended Emerson and Hatton's (2007b) analysis. In line with the diagnostic overshadowing hypothesis it was expected that children with LD and those with dual diagnosis would access specialist mental health services at similar levels and less than children with just a psychiatric diagnosis.

(b) Identify factors associated with service use: The variables considered were maternal mental health, family socioeconomic status, family composition, LD and psychiatric diagnoses.

Materials and methods

Participants

The ONS (2004) survey presents data from a randomly selected sample, stratified by postcode, age and sex. Families were identified using child benefit records and were recruited via mail invitations. Families received a letter about the survey and if they opted to participate, information was collected using interviews with the parents and children and postal questionnaires with teachers. There was a 76% response rate and 7,977 children were assessed. Table 1 presents the sample's characteristics and the current analysis presents data from:

- 7074 typically developing children (defined as children who did not receive a psychiatric diagnosis and who did not meet the criteria for LD)
- 634 children who received an International Classification of Disease-10 diagnosis (ICD-10: World Health Organisation, 1994)
- 165 children who met criteria for LD
- 104 children with dual diagnosis

Measures

Service use

The survey questioned parents about their use of eleven types of informal and professional help. The current analysis grouped these sources of help according to whether they needed a referral and their degree of specialisation. The groupings considered were:

- Non-professional support (comprising family, friends, telephone helpline, self-help groups and internet help)

- Primary care (services that did not need a referral) comprising general practitioners and teachers
- Social work/ education services (services that needed a referral) comprising social work and special education services
- Mental health services (specialist services) comprising CAMHS and adult mental health services

An overall category of professional help was also considered, comprising all the services detailed above plus specialist physical health services.

Learning Disability

Using an operational definition of LD (Emerson & Hatton 2007a), children were classified as having a LD if:

- Their carer reported they had LD and their teacher indicated they had a difficulty in reading, maths and spelling or they had a developmental quotient (teacher estimated developmental age divided by chronological age) two or more standard deviations below average.
- Their teacher reported they had difficulties in reading, maths and spelling and they had a developmental quotient two or more standard deviations below average.
- Their carer reported they had LD and had been concerned about their language development in the first three years of life.

The frequency of LD using this definition is slightly higher than the assumed prevalence rate, and this might be because the definition incorporates some borderline cases (Emerson & Hatton, 2007b). However, frequency of LD did vary according to age, gender and social deprivation, in a manner consistent with epidemiological data and the literature (Emerson, 2005).

Psychiatric diagnosis

Psychiatric diagnosis was defined as the presence of any ICD-10 diagnosis. These diagnoses were derived from the Developmental and Well-Being Assessment (DAWBA: Goodman et al. 2000). This interview assessment combines parent, child (if 11 years or older) and, if available, teacher information. The DAWBA indicates whether a child has had a diagnosable mental health problem during the previous month and has good discriminative and concurrent validity (Emerson, 2005, Emerson & Hatton, 2007a).

Socioeconomic status

A composite variable (SEP) was created combining information on family poverty, parental employment, maternal level of education and the child's experience of negative life events. Family composition was considered as a separate variable (single parent status versus other).

Maternal mental health

The survey assessed maternal mental health using the 12-item General Health Questionnaire (GHQ: Goldberg & Williams, 1988). Hu et al. (2007) developed a two-factor model of the GHQ, scored using a likert scale. Their positive mental functioning and affect factor (GHQ items 1,3,4,7,8,12 reverse scored) was calculated to indicate maternal positive mental health. Using a cut-off of three in the total GHQ score (Green et al. 2005) another variable was created to indicate the presence of maternal emotional disorder.

Procedure

The ONS (2004) database was obtained from the Economic and Social Data Service. The service contact of four comparison groups was explored (children ‘typically developing’, ‘with LD’, ‘with psychiatric diagnosis’ and ‘with dual diagnosis’). Then correlates of service use were investigated using multivariate logistic regression models.

Results

Service contact

Table 2 shows the rate of service contact amongst the four groups. Receiving any form of help was higher amongst children with psychiatric diagnosis (with and without LD). Seeking professional help showed a similar trend but over half of the children with only LD had no contact with services (53.3%). Children with LD had most contact with primary care services and had limited contact with social work and education services. Children with dual diagnosis had similar rates of contact with specialist mental health professionals as children with psychiatric diagnosis ($\chi^2 = .94$, $p = .33$) but the figures suggest that only just over a quarter of the most complicated cases reach specialist services.

Service use correlates

There were significant group differences across all the predictor variables considered and LD was associated with an increased risk of family social and economic deprivation. This association was highest in children with dual diagnosis, which suggests these factors may be additive (see table 1). A Mann Whitney test indicated that the distribution of age was similar across LD (p =.63), but different across psychiatric diagnosis categories (p<.001). The correlation coefficient for the measures of maternal emotional disorder and maternal positive mental health was -.58, (p<.001: Pearson's two-tailed), which does not prohibit these variables being entered jointly into the regression analyses.

Binary logistic regression was conducted using the PASW statistics 18 programme (table 3). Having a LD was associated with accessing all professional services, though the contribution of this variable, relative to having a psychiatric diagnosis, was small. Family socioeconomic deprivation increased the odds of accessing professional and social work and education services. Maternal emotional disorder correlated with all service access, except specialist mental health teams. Positive maternal mental health was associated with less access to social work and education services. Younger children had more contact with professional services overall, and in particular with social work and education services, whereas, boys had greater contact with all services. Family composition was not correlated with service contact.

Discussion

Service contact

The first aim of this secondary analysis was to explore service contact among children with LD, controlling for psychiatric diagnosis. Adding to the characterisation presented by Emerson and Hatton (2007b) LD service use was compared to typically developing children and services were grouped into categories of access.

Children with LD use services more than typically developing children but overall a substantial proportion of children with LD (especially those without psychiatric problems) do not access professional services consistent with previous research (Benedict, 2006, Newacheck et al. 1998). Children with LD had most contact with primary care services, indicating that many children are not receiving specialist support. However, the definition of LD employed in the current analysis might have incorporated some borderline cases, who would not reach service eligibility criteria.

Contrary to the diagnostic overshadowing hypothesis children with dual diagnosis accessed more services than children with only LD. Their service access rates were directly comparable to those of children with just a psychiatric problem, suggesting that in clinical practice clinicians are able to recognise mental health problems in children with LD. A higher percentage of children with dual diagnosis in this sample accessed mental health services than in Witt et al's. (2003) study, despite a more stringent definition of LD being used.

However, it is concerning that about two thirds of children with psychiatric disorders (with and without LD) did not access specialist services. This figure may represent limited access for these groups of children, however some methodological limitations of the current study may go some way in explaining the trend. It is possible that DAWBA generated diagnoses (based on symptoms in the last month) could have identified children awaiting service-based diagnosis or referral. Another possibility is that the current figures might under-represent contact as information about service use was based on parents' retrospective recall, which is known to be vulnerable to biases

(Shivram et al. 2009). Unfortunately the current analysis could not verify service use or investigate the frequency and duration of service contact.

Floyd and Gallagher (1997) found that children with LD and behaviour problems accessed most services, presumably because these behaviours caused parents and professionals most concern. This study defined psychiatric problems as any ICD-10 diagnosis and this included, among others, hyperkinetic disorder, conduct disorder and autistic spectrum disorder. So, in the current analysis behavioural disturbance might have led to increased service use amongst dually diagnosed children. Further analysis would be needed to explore whether LD overshadowed psychiatric diagnoses such as depression and anxiety.

Service use correlates

In the regression models, other than male gender, psychiatric diagnosis, LD and maternal emotional disorder were the main correlates of service access. Contrary to Dura-Vila and Hodes (2009) family composition did not predict service use, suggesting their results might have been influenced by including foster families in their analysis. Family socioeconomic status did increase the odds of accessing some services corroborating previous findings that service use associated with families having increased financial burden (Benedict, 2006, Witt et al. 2003).

It is interesting that maternal emotional disorder increased the odds of accessing some services, whereas maternal positive mental health reduced it. The data is cross-sectional, so cause and effect cannot be implied. It is possible that maternal positive mental health means that families have sufficient resources and do not need professional support. However, it is equally possible that, as accessing services can still be experienced as stigmatizing by some parents (Bradby et al. 2007), contact leads mental health to deteriorate.

Limitations

In the regression models many of the variables had limited predictive power. This might have been because service use was limited, but may also relate, in part, to how these variables were created. The potential problem with the LD categorisation including borderline cases has already been referred to. Psychiatric diagnosis was based on the DAWBA which has not been validated for children with LD. Psychiatric problems may present differently in children with LD and they may be less able to complete interview assessments because of less access to, or ability to report, internal states (Emerson and Hatton, 2007b). This suggests that some of the children with LD may have had undiagnosed psychiatric problems and so the possibility of diagnostic overshadowing cannot be dismissed.

Clinical Implications

Generally, children with LD had less service contact than children with psychiatric diagnoses and access barriers need to be further explored. When families do access services, interventions should consider how to enhance maternal wellbeing and as socioeconomic status predicted contact with professional services, policy initiatives that seek to reduce the discrimination children with LD confront remain a priority. Some interventions to facilitate service access have been trialled in the UK. For instance, Raghavan et al. (2009) found that a specialist liaison service increased service contact for young people with mental health problems, LD and Pakistani or Bangladeshi origin.

It is promising that children with dual diagnosis did not have less contact with specialist mental health services. To consolidate best practice measures that can identify psychiatric diagnosis in LD, such as the Diagnostic Manual- Intellectual Disability (DM-ID: Fletcher et al. 2007), should be used routinely.

Future research

To further explore diagnostic overshadowing the frequency children with LD, who have anxiety or depression, are treated by mental health services should be explored. However, service contact does not necessarily imply children's needs are being met (Russell et al. 2010) and research needs to consider the factors that enhance families' experience of services. For instance, research could investigate if care coordination increased service uptake (Witt et al. 2003) and explore what impact FCC has on engaging families (Dunst et al. 2002).

Summary and conclusions

Children with LD in the UK use few services. However, there was no evidence of diagnostic overshadowing and, other than male gender, psychiatric diagnosis, LD and maternal emotional disorder were the main correlates of service use. Future research needs to explore families' perceptions of the support they receive.

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Tables

Table 1. Participant characteristics

Characteristic (a/b)	**No diagnoses**	**Psychiatric diagnosis**	**LD**	**Psychiatric diagnosis & LD**	**Group comparison** (d)
Male gender	3558 (50.3%)	375 (59.1%)	104 (63.0%)	74 (71.2%)	43.811**
Maternal emotional disorder	1378 (20.0%)	292 (47.4%)	43 (29.7%)	34 (38.2)	259.65**
SEP (low) (c)	1689 (26.4%)	243 (43.8%)	62 (46.3%)	39 (48.8%)	240.05**
Family poverty	1689 (26.4%)	243 (43.8%)	62 (46.3%)	39 (48.4%)	114.35**
Neither parent working	926 (13.4%)	183 (29.2%)	46 (31.1%)	48 (48.5%)	224.49**
Child experienced one or more negative life event	3093 (44.7%)	429 (69.2%)	81 (56.6%)	64 (68.8%)	159.66**
None/ limited maternal education	2040 (29.5%)	305 (49.3%)	75 (51.4%)	53 (58.2%)	158.58**
Single parent	567 (8.1%)	74 (11.7%)	19 (11.5%)	15 (14.4%)	15.80**
Child age	10.46 (3.41)	11.44 (3.30)	10.12 (3.22)	10.96 (2.88)	**
Maternal positive mental health	12.06 (1.90)	10.95 (2.93)	11.91 (2.14)	11.04 (2.29)	**

a. Values for binary variables are frequency counts and percentage of the group classified as matching the variable.

b. Values for non-binary variables are means and (standard deviations).

c. SEP (low) is a composite of family poverty, parental employment, child life events and maternal education.

d. Group comparison for binary variables was conducted using Chi Square analysis. Comparison for non-binary variables was conducted using Kruskal Wallis pairwise comparison.

** p<.001

Table 2. Frequency of service contact amongst the comparison groups.

Type of help sought	**No diagnoses**	**Psychiatric diagnosis**	**LD**	**Psychiatric diagnosis & LD**	**Group comparison** (a)
Any help *Non-professional help, professional help, other help*	1532 (21.7%)	467 (73.7%)	84 (50.9%)	86 (82.7%)	1009.65**
Non-professional help *Family, friends, telephone helpline, self-help groups, internet*	693 (9.8%)	221 (34.9%)	26 (15.8%)	38 (36.5%)	399.75**
Primary Care *General practitioner, teacher*	1057 (14.9%)	372 (58.7%)	75 (45.5%)	75 (72.1%)	956.35**
Social work/Education services *Social worker, education services*	161 (2.3%)	161 (25.4%)	29 (17.6%)	42 (40.4%)	1008.68**
Specialist Mental Health *Specialist mental health services, adult mental health services*	72 (1.0%)	149 (23.5%)	8 (4.8%)	29 (27.9%)	1146.44**
Professional help *Specialist physical health, mental health, social work and education and primary care services*	1132 (16.0%)	412 (65.0%)	77 (46.7%)	78 (75.0%)	1082.48**

a. Group comparison conducted using Chi Square analysis: ** p<.001

Table 3. Factors predicting service access

	Non-Professional help model	**Professional help model**	**Primary care model**	**Social work/ Education service model**	**Specialist mental health service model**
Model Fit (χ^2)	363.45 **	906.15 **	793.64 **	566.69 **	555.26 **
Predictor Variables	Odds Ratio (95% CIs)	Odds Ratio (95% CIs)	Odds Ratio (95% CIs)	Odds Ratio (95% CIs)	Odds Ratio (95% CIs)
Age	1.01 (.99-1.03)	.98 * (.96-1.00)	1.01 (.97-1.05)	.98 * (.96-1.00)	1.01 (.97-1.06)
Learning Disability	1.40 (.99-1.98)	4.29 ** (3.12-5.90)	4.68 ** (3.22-6.79)	4.41 ** (3.22-6.03)	1.88 ** (1.18-3.01)
Psychiatric Diagnosis	4.17 ** (3.44-5.06)	7.87 ** (6.52-9.51)	9.16 ** (7.12-11.79)	6.70 ** (5.57-8.66)	22.19 ** (16.18-30.43)
SEP (low)	1.00 (.85-1.18)	1.15 * (1.01-1.32)	1.41 ** (1.10-1.82)	1.08 (.94-1.25)	1.05 (.77-1.43)
Single parent	1.24 (.96-1.58)	.94 (.75-1.18)	1.03 (.70-1.51)	.97 (.77-1.21)	.95 (.59-1.53)
Maternal emotional disorder	1.98 ** (1.63-2.40)	1.64 ** (1.38-1.94)	1.45 * (1.06-1.98)	1.65 ** (1.39-1.96)	1.44 (.98-2.11)
Maternal positive mental health	1.00 (.96-1.04)	.97 (.94-1.01)	.99 (.95-1.02)	.93 * (.87-98)	.95 (.88-1.02)
Male gender	1.06 (.91-1.22)	1.50 ** (1.33-1.70)	1.51 ** (1.34-1.72)	1.50 ** (1.18-1.92)	1.51 ** (1.12-2.04)

Footnote: CIs = Confidence Intervals * $p<.05$ ** $p<.001$

Empirical Paper B

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Family-centred care-giving in the Incredible Years parenting intervention

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Abstract:

Background: Family-centred care (FCC) is a commonly used service model in child disability services in the United Kingdom (UK) and can be applied to family interventions. Its concepts include partnership, collaborative decision-making, information sharing and empowering families. The Incredible Years (IY) parenting course is increasingly offered to parents whose children have learning disabilities (LD), however, parents' views of the IY course have not been explored to see if they perceive the course as providing aspects of FCC.

Methods: Parents whose child had LD and who had attended an IY toddler course run by a Specialist Children's Service were recruited. Participants completed pre and post measures of their child's behaviour and their course aims. When the course ended they completed a service satisfaction questionnaire and attended a focus group, which explored their experiences of the course. Data were analysed using descriptive statistics and framework analysis.

Results and conclusions: Five people attended the focus group. Parents' commented positively on several aspects of the course that related to FCC. For instance, they commented on the facilitators' interpersonal skills, their responsiveness to families' concerns and the benefit of making connections with parents in similar situations. Unfortunately, the small number of respondents means only tentative conclusions can be made, and to explore FCC further, families need to be involved in designing service related research.

Introduction:

Family-Centred Care (FCC) is endorsed in the United Kingdom (UK) and is based on two principles: that the family has an important role in children's development and that families' coping abilities are influenced by how support is provided (Dempsy et al. 2009). Its core concepts include; parental involvement in decision-making, collaboration, partnership, mutual respect, support, focusing on strengths, flexible services, information sharing and empowerment. This list of concepts can be divided into two skill sets: partnership or relational help-giving and participatory help-giving, where professionals provide practical help and resources (Dunst et al. 2002).

Children's disabilities can create social and psychological burdens for families (Bella & Mahoney, 1998), making FCC particularly relevant. Of course, parents can have positive experiences with their child despite their disability (e.g. Kayfitz et al. 2010) and not all research endorses service contact as an important factor in parental adaptation (McConachie, 1994). Nevertheless, maximising parents' coping strategies is of prime importance (Matson et al. 2009) because capacity to cope can mediate parental stress and family accommodation (Hastings, 2002). For instance, Dunst et al's. (2007) review found that parents' sense of self-efficacy and their satisfaction with services were strongly related to their perceptions of FCC. Child behaviour and functioning, personal and family well-being and parent behaviour were also significantly, but less strongly, associated with FCC. However, their meta-analysis did not focus exclusively on children with LD.

Not all studies are consistent with Dunst et al's. (2007) review findings. Dempsy et al. (2009) found no association between FCC and parental feelings of competence, enjoyment and confidence, though the measure of competence used was not well-validated. Generally, parents of older children perceive services as providing less FCC (McConachie & Logan, 2003). This may be because parents are naturally more involved in the care of younger children (Raghavendra et al. 2007). Additionally, parents of children with greater difficulties often access more services and perceive less FCC (Law et al. 2004), though Dickens et al. (2011) did not find this association when services were provided at a single location.

Few studies have explored FCC in the UK. McConachie and Logan (2003) found that having a care coordinator was associated with a favourable perception of child disability services. More recently, James and Chard (2010) interviewed ten parents using an early intervention service for pre-school children with disabilities in Ireland. Parents said interpersonal relationships with professionals, professional competence and skill were important. They did not think there was adequate support at critical times, continuity of service or provision of information.

FCC interventions

The Incredible Years (IY) parenting course (Webster-Stratton, 2001, cited by McIntyre, 2008a) aims to promote positive parent-child relationships and reduce child challenging behaviour by supporting parents to develop parenting techniques based on social learning theory. It can be viewed as an application of FCC because it aims to establish collaborative partnerships between parents and professionals and enhances parents' coping strategies. During the course parents choose goals for themselves and their child and group rules are negotiated, so the course is designed to be adapted to the needs of the parents attending (Webster-Stratton, 2009). Children's strengths as well as difficulties are highlighted and the course aims to promote positive parent-child relationships, (McIntyre, 2008) which are likely to improve family functioning. The basic course modules include information to help parents manage their own stress and anger (Roberts & Pickering, 2010) and the group format encourages parents to share and support each other. The course additionally aims to help parents to advocate for themselves (Webster-Stratton, 2009). These course methods and aims are consistent with FCC concepts of focusing on strengths, empowerment, providing support and information, parental involvement in decision-making and collaboration. Patterson et al. (2005) interviewed parents who attended various IY courses suitable for children aged two-to-eight years. Twenty-two respondents had attended at least 50% of the course, three had not attended and one had dropped out. Seven had children with clinically significant behaviour problems, but none had disabilities. Parents said they had gained confidence and that learning play techniques had improved their relationship with their child. They appreciated being supported non-judgementally rather than instructed.

McIntyre (2008a) provided an adapted IY Toddler course to parents whose children were two-to-five years old and had mild-to-moderate LD. Post-course, parents showed more positive parenting behaviours and there was less observed child challenging behaviour. McIntyre (2008b) compared the outcomes of families of children with LD attending an

IY course to those receiving treatment as usual. Children whose parents attended the IY course demonstrated less challenging behaviour. Recently, Roberts and Pickering (2010) provided an IY course to eight parents whose children had conduct, social communication and/or complex neuro-developmental difficulties. They concluded that the IY course improved parental mental health and reduced the impact and frequency of some child challenging behaviour.

To extend research on FCC in the UK, this study aimed to explore if parents, whose child had LD, perceived an IY course to provide aspects of FCC. If IY courses can be delivered in a manner consistent with FCC, it supports the use of this intervention in services promoting FCC.

Method:

Participants

Ten parents whose children had LD and who were attending an IY course were invited to participate. Families were recruited to the IY programme when it was relevant to their presenting concerns. As in McIntyre (2008a) parents who had children older than seven and whose children had severe LD or significant motor or sensory problems were excluded.

Seven parents initially agreed to participate and of these four mothers and one family carer attended the focus group. These carers represented four children who had LD:

Respondent	**Demographic information**
1	This lady was aged 26-30 years. She was divorced and unemployed and had GCSE or equivalent level of education. She stated her ethnicity was English and was first language Welsh. She had one child who was three-to-four years old.
2	This lady was aged 51-55 years. She was married and employed and had post-degree level education. She stated her ethnicity was English and she was first language English. She had one child aged seven.
3	This lady was aged 31-35 years. She was co-habiting and employed and had GCSE or equivalent education. She did not state her ethnicity but was first language Welsh. She had two children and the child she attended the IY course for was two-to-three years old.
4	This lady was aged 41-45 years. She was married and unemployed and had GCSE or equivalent education. She stated her ethnicity was English and she was first language Welsh. She had five children and was attending the course for her child aged three years.
5	This lady was a family member of another respondent and had attended the IY course. This family member had a significant child care role for respondent's child.

The IY course

The 12-week IY Toddler course was provided by two facilitators from a Specialist Children's Service (SCS). The course was adapted according to the changes implemented by McIntyre (2008a). For instance, the 'time out' technique was omitted and parents were advised on how to predict and avoid problem behaviour by collecting information about antecedents and consequences. Information was provided about local support groups and when discussing vignettes, parents were encouraged to identify which aspects did not relate to their child, as well as the key points that could be applied. Parents were additionally provided with the opportunity to discuss the blessings and the challenges of raising a child with LD. Two further modifications were made: parents were encouraged to consider their own self-care and the emphasis on academic coaching was reduced.

Measures

Participants completed three questionnaires:

- The Client Satisfaction Questionnaire (CSQ: Larsen et al. 1979) asks about satisfaction with services and has high internal consistency (Schie et al. 2004) and adequate validity (Siebes et al. 2007).

- Parents were asked to rate their child's behaviour during the proceeding month on the Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997). The SDQ covers child hyperactivity, emotional symptoms, pro-social behaviour, conduct and peer problems and pro-social behaviour. It has good predictive and concurrent validity (Goodman, 1997), inter-rater reliability, test-retest stability, internal consistency (Goodman, 2001) and factorial validity (Sanne et al. 2009).

- Parents were asked to list three problems they most wanted ameliorated and indicate their severity by marking on a line (Parent Defined Problems Questionnaire (PDPQ): Scott et al. 2001). A ten-point scale was added to quantify ratings.

Procedure

Ethical approval was obtained for the study and all participants provided informed consent. Parents completed the SDQ and the PDPQ at the start of the IY course. At the end of the course they completed the SDQ, the PDPQ and the CSQ and attended a focus group. In the focus group the moderator followed a question guide (Table 1) and at the end of the discussion, the moderators' initial understanding of respondents' views was checked with the participants. The group was recorded and transcribed.

Framework Analysis (Ritchie & Spencer, 2002) guided the interpretation of the focus group. Indexing the ideas raised enabled patterns and associations to become evident and the context, in which ideas arose, to emerge. The main themes, their sub-components and representative quotes were charted and summarised. Participants' perceptions were compared and connections highlighted. These themes and example quotations were discussed in supervision to provide an audit trail.

Results:

Focus group participants said the course had provided them with assistance. On the PDPQ the average group score reduced from 7.53 (pre-course) to 5.93 (post-course). The averaged rating on the CSQ after completing the course was 76.6, indicating high satisfaction. In terms of child behaviour, there were improvements on the SDQ total behaviour score post-course, but the impact of child behaviour was perceived to have increased (table 2). On the SDQ total difficulties and impact measures there was a high amount of variability between participants' ratings (table 3). So, even a fairly homogenous group of parents responded to the course somewhat differently. However, it should be noted that pre-course, two respondents completed the wrong age version of the SDQ, although there are minimal differences between the versions. Additionally three missing ratings were replaced with participant's mean rating for that sub-scale. The main themes relating to FCC from the focus group are discussed.

Credibility

Psycho-education was perceived as most beneficial when it was specific to parent and child needs. Generic parenting information was less helpful: *"it just seemed a bit dismissive in the book you know, that it isn't such a big issue and yet to us it's a massive issue"* (p2). Similarly, a respondent commented about the video vignettes (shown to demonstrate parenting techniques): *"..they had a tantrum which was nothing compared to the kind of tantrums you get with a special child."* (p2). Although more adapted to the group, participants' thought role plays could not be 'real' enough to be helpful: *"..it was* *a bit too unrealistic because....it was just too calm, ..."* (p5). Information was judged specific and relevant when the facilitators had an ongoing relationship with the family: *"if she's your psychologist, it does make a difference because, you know, she would know the child really well."* (P4). Similarly, information from other parents was discussed positively because it came from people who understood the situation families were in: *"you might get advice from somebody else just being there, done that, worn the t-shirt"* (p8).

Partnership

The facilitators were described as *"caring"*, available listeners and one participant summarised that the course had: *"Not made"* her *"feel like a bad mother"* (p22). Parents who had worked with the facilitators before, spoke of the long-term nature of these partnerships being valuable: *"...also I think that any changes, you know, you can talk to her about, because she's seen through the years...."* (p4). When the facilitators did not know the child well, this was perceived negatively: *"I know they do know their work but every child isn't the same, they should visit or see the child, to get to know where we're coming from"* (p4). In this participant's case, part of the problem seemed to relate to the facilitators not being part of their normal care team: *"the women that did it, it's for (place) isn't it, and (place) is totally different..."* (p7). So for them, the IY course had not been co-ordinated with the other services they received.

Responsiveness

Facilitators' availability and responsiveness were important. Parents implied they had a sense of continually waiting for services to respond: *"Because she's only working one day a month...there's a bit of, err a lack of communication and... things are not moving quick enough"* (p7). Some respondents also reflected on waiting for their child: *"You know, you can't expect the child to listen to you straight away,...If you gain a yard today and then it might be just a foot tomorrow, but at least the foot has stayed"* (p14). Although this was phrased optimistically, the gist of the comments was that 'waiting' created an ongoing uncertainty. The IY course provided a different experience: *"...if you had a problem during the time you were here you could get help, you know, quite quickly,....I could do something straightaway"* (p6).

Power dynamics

The responsiveness and specificity of the course provided one participant with a sense of empowerment because: *"Sometimes that's the biggest barrier- that you feel no-one understands"* (p23). The facilitators were viewed as pro-active and were seen to adapt information to suit attendees' needs and this fostered parents' sense of control: "*...she moved topics up that we thought were more important"* (p4). In contrast, participants' felt their interactions with some services were not as collaborative: *"...we feel, don't we, that we've got to get in touch with err, with them all the time and not them phoning us and see how we're doing, how we're managing and that."* (p7) and *"..they have a way and you fit their way or you don't..."* (p15). Another participant discussed an incident at her child's school and implied that staff did not always abide by the rules she was expected to follow. One participant joked that staff should be sent some of the IY information. The exchange implied that professionals needed to gain parents' trust. IY facilitators gained parents' trust because their style was collaborative and the course was described as a *"safe place"*.

Social support

All participants said they derived support from meeting other parents: *"It's nice to speak to people who've gone through the same problems that you have"* (p23) and *"..just meeting up with your friends every week and it was easier to open up about things"* (p9). However, one participant acknowledged that different experiences still needed to be sensitively negotiated: *"... because if you really did imitate something that other people didn't like or were upset by that would be difficult wouldn't it in this kind of group"* (p16).

Importance of the child

Participants endorsed advocating for their children and one respondent said that recording her child's progress meant that: *"...at least the two people who read my reports saw it.."* (p10). She thought a good aspect of the IY course was that there was a focus on strengths as well as problems: *"not that I can't see the good in her, I always do, but for other people to"* (p10). Parents' discourse also contained examples of advocacy: *"As I say, (child's) not actually a naughty, naughty boy, if you know what I mean"* (p13). However, one participant spoke about needing to balance the needs of different family members. She concluded: *"A child could rule your life, it has done for me"* (p20). Parents also reflected on how other people's responses to them and their child impacted on the family. This could prevent IY strategies being used. One respondent spoke of not being able to use her normal parenting strategy whilst shopping: *"It was just other people make it so that you can't, or, or how you perceive other people makes it so you can't"* (p12). Participants did not say if the course had helped them negotiate this barrier.

Self-change

Participants' talked more about the IY course changing them, than their child. For example, one participant commented: *"Before I wouldn't have had the guts to stick it out"* (p10). Self-change was discussed positively, with the exception that one participant reflected on the emotional impact of using IY strategies: *"Well I've started with (child) erm totally ignoring.....he really cries. He breaks, do you know, I want to cry as well with him"*.

Acceptance

The IY course often supports parents to change family routines. How participants responded to this seemed to relate to the extent they had accepted their child's disability. Therefore, participants had different ideas about what aspects of the course had been helpful. For example, one parent talked positively of adapting the family routine to suit their child's language needs, whereas another parent said that: *"Well my goal was to get (child) talking. I'm still stuck down there.... So that one's failed, well, completely..."* (p6). Similarly, one participant said the course provided a sense of perspective: *"you know, there is issues, but there's always a lot of joy"* (p19), whereas others talked more of hoping things would change for them and their child: *"So it's a constant battle with him. But we'll get there, I will"* (p12).

Discussion:

The focus group feedback suggested that the IY course was considered to provide aspects of FCC and respondents referred to aspects of relational and participatory help-giving (Dunst et al, 2002). Although different terminology was used respondents referred to many of the concepts of FCC when discussing their experiences of the course.

The focus group themes of 'power dynamics' and 'responsiveness' incorporated respondents' impressions that they participated in deciding how the course content was prioritised, so they were involved to some extent in decision making. The theme of 'responsiveness' also relates to the FCC concept of providing flexible services.
The themes of 'self-change' and 'importance of the child' illustrated some ways in which the IY course focused on and enhanced strengths in the parent and child. One respondent felt empowered by how the facilitators responded to her families' individual needs and the course focus on strengths.

Some FCC concepts received more nuanced support. All respondents reported they had gained information from the course, but they thought some of the content, e.g. the video vignettes, lacked credibility. However, all the respondents talked positively about the course enabling parents to share information with each other and this would fulfill the FCC concept of information sharing. Additionally, when the facilitators were perceived to know the family they were judged to share credible information. In general, the course was perceived to provide good support. The main exception was that respondents' did not say whether the course had helped them to manage reactions from members of the public to their child with LD and their use of IY strategies.

Finally, in the themes of 'partnership', 'responsiveness' and 'credibility', respondents referred to FCC concepts of collaboration, partnership and mutual respect. All respondents made some positive comments on these aspects of the course, which can be summarised as the course being "a safe place". However, respondents also suggested that the facilitators taking time to meet with the child and family pre-course would strengthen these aspects of FCC in the IY course.

At the end of the course, similar to Roberts and Pickering (2010), some child problem behaviour remained, though as in McIntyre (2008, 2008b), most parents viewed the behaviour they wanted ameliorated at the start of the course as less of a problem. It is interesting that the impact of other behaviour problems was perceived to have increased by some parents. Maybe the course had led some parents to focus even more on behaviour.

Participants' experiences were similar to parents' reports in Patterson et al. (2005): they reported gaining in confidence, felt supported and found the group non-judgemental. However, they talked more about self-change than about learning techniques or improving their relationship with their child. These differences might be because

Patterson et al's. (2005) parents did not have children with LD. Participants also rated the course positively despite having to travel to a different clinic to attend. In previous research, attending different clinic bases has been associated with less perceived FCC (Law et al. 2004). Perhaps the impact of multiple-site working was reduced because the SCS served a rural area and parents were used to travelling to receive services.

Participants talked most about the personal aspects of the relationships in the group and they endorsed that it was important for professionals' to spend time getting to know and understand families (McConachie & Logan, 2003). When respondents spoke about wider services they shared some of the concerns that James and Chard's (2010) parents' expressed about continuity of support and access to relevant information. Parents spoke frequently about self-change, which is consistent with Roberts and Pickering's (2010) finding that their most improved outcome measure was parental well-being.

Some of the factors suggested in previous studies, did not seem to influence parents' perceptions of FCC. Child behaviour did not seem to mediate how FCC was perceived. Similarly, participants' acceptance of their child's disabilities influenced what they found helpful but did not affect whether they perceived the course as providing support consistent with FCC (Dempsy et al. 2009). It seemed that parents' acceptance of their child's LD impacted on how they viewed IY parenting strategies and whether they reported positive outcomes. This highlights the problem with relying exclusively on informant report. The most influential factor was that parents talked about FCC in the context of reflecting on positive self-change. Respondents' reports would be consistent with a model whereby, the IY course increased parents' self-efficacy and well-being, and this influenced their perception of FCC (Dunst et al. 2007).

Limitations

The focus group represented the experiences of a small number of carers of young children with LD. Previous research suggests that parents of older children might have perceived less FCC (McConachie & Logan, 2003). The participants were an established group and were interviewed when they were trying to maintain group cohesion at the end of the course. Participants seemed to gain social support from group cohesion and this could have discouraged respondents from expressing contradictory views. An additional concern about the range of views obtained was that it became evident during transcription that criticisms of the course were quickly counterbalanced with positive statements. The respondents might have been reluctant to express criticism in case the course was stopped or the facilitators were upset. However, some differences in opinion were apparent and it was decided not to corroborate the information with individual interviews, because the research was interested in the groups' reflections. Questionnaires provided additional information about how parents responded to the course, but observation data would have been valuable, especially considering the range of ratings for child behaviour.

Some participants had worked with the facilitators before commencing the IY course and it is possible some of their reflections were influenced by these long-term relationships. However, it was interesting that all participants endorsed how important it was that the facilitators knew the family and the child. They indicated this increased facilitators' credibility and enhanced the perception of working in partnership. IY facilitators meeting the family and child before the course would be one practice recommendation that would make the IY intervention more consistent with providing FCC.

Clinical implications

Parents endorsed running separate IY courses for families whose children have LD and gaining social support was important. It would be beneficial if courses provided the option of continued informal meetings. As parents' acceptance of their child's LD influenced their experience of elements of the IY course, and self-change was a significant theme, both parents and facilitators would benefit from course preparation. Facilitators could begin to form partnerships with parents by making home visits before the course, meaning parents would be more likely to believe that facilitators understood the family situation and course content could be made specific and relevant. Similarly, problem-solving group scenarios might be more credible than role-playing or watching vignettes.

Conclusions

The study found positive perceptions of many FCC concepts in an IY course provided by a SCS. Focus group respondents commented positively on several aspects of FCC, such as the specificity of information and facilitators' responsiveness and interpersonal skills. However, FCC philosophy highlights that parents should be involved in research as partners, not as participants (Russell, 2004). This research lacked a degree of face validity because parents were not involved in its design. Inviting parents' input could have ensured the research questions were meaningful to parents attending the IY course and might have maximised recruitment to the focus group.

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Tables:

Table 1: Moderator question guide

- What did you like most about the course?
- What did you like least about the course?
- What did you think of the topics covered?
- What did you think of the different presentation formats?
- What topics would you like to have seen included?
- What did you expect the course to be lie and what did you hope to gain from it?
- How were these expectations met?
- How did you feel in the group?
- How did you find talking in the group?
- How did you find the size of the group?
- How did you find putting the things you learnt into practice?
- Was anything difficult?
- Can you give some examples of when you tried out the skills?
- How did the course advice fit with what other workers in the service have suggested?
- How has the course impacted on your relationship with your child/ children?
- How did the course influence your parenting?

Table 2: Pre and post course mean SDQ scores (N=4)

SDQ	**Pre-course Mean (Standard Deviation)**	**Post-course Mean (Standard Deviation)**
Emotional Symptoms Scale	3.25 (2.22)	2.50 (2.89)
Conduct Problems Scale	5.25 (2.22)	4.25 (2.75)
Hyperactivity Scale	7.50 (1.00)	8.50 (1.00)
Peer Problems Scale	3.75 (1.00)	2.50 (1.73)
Pro-social Scale	4.25 (1.89)	5.00 (0)
Total Difficulties	20.75 (5.68)	17.75 (7.36)
Impact rating	3.50 (1.29)	5.50 (3.11)

Table 3: SDQ response range

SDQ	**Pre-course range**	**Post-course range**
Total Difficulties	15-27	10-25
Impact rating	3-5	2-9

Figures:

Key Messages:

- IY courses can be implemented consistently with a FCC approach
- After attending an IY course, parents whose child had LD commented positively on the facilitators' interpersonal skills, their responsiveness to families' concerns and the benefit of making connections with parents in similar situations.
- For studies to gain face validity, families need to be involved in designing and conducting research into FCC

Contribution to theory and clinical practice

Contributions to theory and clinical practice

This thesis investigated families' engagement with services when their children had learning disabilities (LD). McCarthy and Boyd (2002) suggested that first the extent children with LD access services needs to be determined and second the effectiveness of service interventions and families' views of services should be addressed. Previous research has suggested that children with LD have unmet service needs (Floyd & Gallagher, 1997), especially when they have co-morbid psychiatric diagnoses (Witt et al. 2003). Amongst the families who have service contact, research has explored whether interventions perceived to apply family-centred care (FCC) are associated with greater family satisfaction and better outcomes. The concepts of FCC include collaborative decision-making, information sharing and empowerment. A particular area of interest is how parents and professionals work together.

However, few explorations of service access or FCC have been conducted in the United Kingdom (UK). This thesis comprises three papers consistent with McCarthy and Boyd's (2002) research agenda:

- A secondary data analysis of a UK-representative sample investigated the service contact of children with LD
- A research paper explored FCC in an Incredible Years (IY) parenting course
- A review considered the key ingredients of Parent Professional Partnership (PPP)

The outcomes of these papers have linked themes. Children with LD accessed less services than children with psychiatric diagnosis and they had most contact with primary care services that do not need a referral to access (e.g. general practitioners and teachers). However, when children had dual diagnosis (LD and psychiatric diagnosis) there was no evidence of diagnostic overshadowing. Although service access remains limited, it is arguably increasingly important to consider how services deliver family interventions. Maternal mental health was one correlate of service access and this finding picks up the literature review theme of emotional support being perceived as important in PPP. Other key themes in PPP were negotiating power dynamics, establishing an interpersonal relationship and consideration for the child. Promoting advocacy and empowerment were also highlighted. The IY parenting course intervention was effective in reducing some child problem behaviour and the focus group echoed the literature review themes. For instance, respondents commented on the course facilitators' responsiveness and interpersonal skills. Additionally they discussed how important it was to receive specific information and support from parents in similar situations. Other themes were social support, the importance of the child, power dynamics and credibility.

Implications for future research and theory development

The linked themes from the three papers, in-spite of their different remits, suggest it is possible to consider a core framework when evaluating how interventions are delivered and, by extrapolation, what is important to families when they consider whether to access services. FCC was the framework considered by this thesis and the theoretical and research implications of the findings for this approach are discussed.

Implications for theory development

Service Access

The secondary data analysis indicated that children with LD have less family income, less parental employment and lower maternal education, but over half report no service use. Interestingly, families also accessed less non-professional help (e.g. friends, self-help groups, etc), which would be consistent with the importance given to social support by participants who attended the focus group. FCC is very relevant in this context, but it is difficult to determine a starting point for evaluating its practice. As the secondary data analysis indicated, children with LD access a range of services, so reviewing only LD services is too narrow a focus if 'service contact' is the area of interest. However, it is a reasonable starting point and FCC provides one way to elucidate service access barriers. For instance, perceiving that power dynamics can be difficult to negotiate (highlighted in the review and focus group) may make families' disinclined to seek service help.

This use of the FCC theory would complement current models of service access. For instance, the Health Behaviour Model considers how service users' needs, predispositions and enabling characteristics influence access to health care and what service factors enable access (Anderson, 1995). FCC can enhance the detail this model's conceptualisation of what characteristics of the service enhance or diminish access. FCC would also extend the resource based analysis used in Public Health Framework analysis of service use, which considers the impact of available professionals and workforce training (Schoenwald, Hoagwood, Atkins, Evans & Ringeisen, 2010).

Providing Interventions

According to Scott and Dadds (2009, p1441) "*Nothing is as practical as a good theory*". Unfortunately FCC has become an amorphous term and in clinical practice its elements remain hard to define. For example, it was highlighted in the literature review that partnership is conceived somewhat differently across various services. This enables FCC to be adapted to different work contexts but it impedes theory development.

The breadth of FCC also means it is unclear what outcomes should be measured. For instance, the literature review highlighted that only five papers considered partnership outcomes, but what should be measured as an outcome of partnership is debatable. Additionally, it is easy to loose sight of how FCC theory can be applied within the resource limitations of services. For instance, the literature review proposed a model of effective PPP which emphasised empowering parents, helping them advocate for their child, involving children and negotiating power dynamics. These are high ideals for over-stretched services. This was acknowledged in the model by highlighting that professionals need to be supported by the service they work for.

FCC should be placed in its wider context, as many of its concepts are common to other approaches. For instance, in adult LD services, Person-Centred Planning (PCP) is frequently endorsed. Like FCC, PCP stipulates that the involvement of the service user and their family is very important. When its concepts are examined, they are similar to those recommended by FCC:

Family-centred care	Person-centred planning
Empowerment	Goal orientated, community presence and participation, respect
Collaboration	Develop collaboration
Information sharing	Competency
Partnership	Positive relationships

Meta-analysis shows PCP is associated with some positive outcomes (Claes, Hove, Vandevelde, Loon & Schalock, 2010). However, as in FCC, studies lack control groups, making it problematic to attribute positive outcomes to PCP. Another similarity is that the processes involved in implementing PCP have not been clearly defined. A final similarity to FCC, is that research indicates that professionals are crucial to ensuring service users receive PCP (Robertson, Emerson, Hatton, Elliot & McIntosh et al. 2007). Therefore, the criticisms of FCC can be levelled against similar theories.

Implications for future research

The theoretical discussion of FCC has focused on issues of service access, service provision and the evaluation of interventions. To extend this theoretical framework a number of issues need to be considered and further research conducted. Two areas considered are the absent voices in research and the barriers to further investigation of FCC. Ideas that stimulate research often evolve from professionals' listening to parents' views (Gray, Siebert, Aisen & Gaebler-Spira, 2009). Parents' perceptions are typically sought during audit work as services are expected to seek service-user involvement and participation. For example, the first standard of the National Service Framework (NSF) for Children, Young People and Maternity in England (Department of Health, 2004) requires services to involve children and their parents in planning their care and services. The Welsh standard also endorses children and families participating as partners in service planning and evaluation (Children's Health and Social Care Directorate, 2005). However, it is unclear what value parents place on current consultation methods, such as service satisfaction surveys (MacNeill, 2009).

Absent voices

According to FCC, research and consultation initiatives should evolve out of conversations between services and parents that have established a common value base. Families should be considered partners in research (Russell, 2004) and service users can enrich research by generating different information and interpreting it with greater emphasis on experiential and emotional perspectives (Gillard, Borschmann, Turner, Goodrich-Purnell, Lovell & Chambers, 2010). Involving families in research initiatives can modify relationships between service users and providers. For instance, parents can gain a sense of control and empowerment as they see changes made at their request (Ren & Langhout, 2010).

The literature paper highlighted the voices absent from the discourse about partnership, and by extrapolation, FCC. The views of children and fathers are missing and siblings and service commissioners could be added to this list. FCC aims to strengthen the whole family, so while the opinions of several family members are absent, it is difficult to gauge how FCC is viewed. In this thesis, mainly mothers' perspectives were gained, and this is an important starting point. The review was concerned with the recurring topics discussed in relation to PPP as this had not been summarised before. A summary of the literature will make it easier to identify if parents' have different perceptions, so that these can be explored. However, different perceptions of FCC must be explored systematically (Roberts & Magrab, 1991) and families with various needs and compositions should be sampled, including those who do not engage with services. This last group of families is particularly important as the secondary data analysis highlighted that just over half of children with LD had no contact with services. Future studies could explore whether service access barriers map onto FCC concepts. For instance, does lack of negotiation or information impede service uptake?

Additionally, few studies of FCC have been conducted in the UK: when searching the literature only two UK-studies could be found which explicitly referred to measuring FCC. Studies from other parts of the world cannot necessarily be applied to this country, because the context in which interventions are provided will influence how parents' perceive them, and what outcomes are produced. To understand what FCC means in the UK, further qualitative research is needed about families' experiences of receiving interventions.

Potential barriers to research

An obstacle to this research is that hard to reach groups, such as disengaged families, are likely to remain absent if research continues to rely on 'opt-in' recruitment methods

(Smith, 2008). Additionally, greater use of qualitative research methods will be needed, as these methods can take into account the range of opinions expressed, rather than just extrapolating commonalities. However, qualitative analysis needs to reflect on how the researcher influences the data and the conclusions drawn. For instance, different moderating styles in a focus group may determine whether respondents have a positive experience, especially when the discussion is about emotive subjects. Questions may need to be hesitantly phrased as well as open-ended, as in the current focus group this contributed to the dissipation of anxiety. It is important that participating in research is found to be a positive experience, if hard to reach groups are to be engaged. However, the cost, in terms of data, is that some potential information might not be obtained and the discussion may drift from the research aims, undermining the moderator's role of directing the discussion.

Other barriers to research include time, personnel and financial constraints. Similar to clinical practice, a paternalistic researcher role can appear safer and to have greater compatibility with research remits. This was Morrison's (1996) conclusion about why social workers found it hard to work in partnership with families. Perhaps, organisations need to promote collaborative research practices before researchers will feel confident working in this way.

When considering interventions, one way to operationalise FCC within service constraints is to use FCC concepts as outcome measures. This should be feasible because the focus group suggested that FCC aspects of interventions are recognised by families.

So, after receiving a service, users' self-efficacy and competence in the intervention could be assessed. Research into FCC (e.g. Dempsy & Keen, 2008) has used this type of analysis, but professionals are not assessing users' self-efficacy routinely for service evaluation. Another way to apply FCC within service constraints is to consider its concepts when interventions fail to achieve good outcomes. For instance, during parent training courses, positive parent-child interactions depend on the broader networks in which they occur, including the PPP. If such an intervention is not working, it is worth considering whether families' feel listened to, whether a trusting parent-professional relationship has been developed and if information and decisions are being shared openly (Scott & Dadds, 2009).

Additionally, it is difficult to ensure that all family members can share their perspectives and be involved in research initiatives. Research relies on intellectual skills, which are less accessible to children, especially those with LD. There are also ethical concerns around obtaining children's informed consent (Case, 2001). For other family members, time constraints and other priorities will impact on their ability and willingness to become involved in research endeavours. However, unless more collaborative research methods are routinely employed, the evidence base for FCC will lack a degree of face validity and richness.

In order to involve more families in research, one approach could be to promote the use of participant action research. This approach involves collaboration between researchers and stakeholders in all phases of research, including formulating questions, decision-making, collecting data, interpreting results and disseminating findings (Pullmann, 2009). This way of conducting research is more likely to generate peoples' interest in participating because for families, good research contributes to making interventions more specific to families' contexts and promoting optimal functioning as defined by families (Pullmann, 2009). To summarise, for services to develop and for interventions to be evaluated with ecological validity it will be important to consider the research process and who is contributing to it.

Implications for clinical practice

Government policy (e.g. NSF, Department of Health, 2004) endorses the application of FCC principles but clinical psychologists are also expected to provide evidence-based interventions. There is a chicken and egg scenario about deciding whether to prioritise service access or to strengthen the interventions provided to families who do access services. Floyd and Gallagher (1997) highlighted the need to distinguish between service access and availability. Families might be reassured and assisted to cope by knowing that responsive, supportive services are available. Hence, they might not need to actually have service contact. Therefore, this discussion focuses on how services provide interventions, as this could be important in service access and satisfaction.

Before proceeding to discuss implications for professionals it should be acknowledged that FCC is in danger of remaining paternalistic if responsibility for its implementation remains solely with professionals. Parents need to have joint ownership of implementing FCC, but the literature cites few attempts to work towards this. A recent example of empowering service users to have input into service procedures is the Children's Charter developed by young people with autistic spectrum disorder. Supported by the National Autistic Society, these adolescents made twelve recommendations for Child and Adolescent Mental Health Services. Consistent with FCC, recommendations included providing options about who to meet with and what intervention to receive.

As previously discussed it can be difficult to apply FCC concepts within time and resource limited services. Terms such as 'enablement' and 'empowerment' are widely cited but there are no accepted performance indicators against which to evaluate the impact of these concepts. To maintain a practical focus, the implications for psychological interventions and the therapeutic relationship are considered.

Psychological Interventions

FCC highlights how interventions need to adapted to family needs. This is also recognised in the IY course. Webster-Stratton (2009) wrote about the importance of tailoring IY programme content to the individual family and to the child's developmental, social and emotional goals. Similarly, McIntyre (2008) details how she adapted IY materials for families whose children had developmental disabilities by seeking suggestions from care-givers and professionals about what elements of the course would be most applicable. Focus group participants' endorsed adapting the IY course and discussed the importance of receiving tailored information, which was responsive to their needs. This also links to the review's themes that highlighted how valuable families' find professionals who consider them and their child as individuals.

However, social learning theory (the basis of the IY approach) has few suggestions about how to work with families who do not engage (Scott & Dadds, 2009). Systemic ideas might be helpful in this situation and would be consistent with a FCC approach. For instance, a systemic approach can encourage professionals to understand the presenting problem from different perspectives and to recognise their own role in the system (Hingley-Jones & Mandin, 2007). Unfortunately few papers have considered the use of family therapy (or the use of these systemic techniques) when children have LD. In 2003, Rhodes found only eleven articles about the use of family therapy in this context and a provisional literature search, using web of knowledge (search terms: 'family therapy' and 'learning disab*') revealed no recent papers.

The need for interventions that consider the needs of the whole family was also indicated in the secondary data analysis, as maternal emotional disorder was one correlate of service use. McIntyre (2008) found that only 20% of mothers attending her IY course had a clinically significant decrease in their depressive symptomatology and 24% had a clinically significant increase in symptoms. As indicated in the review, interventions that fail to ameliorate parents' emotional distress are unlikely to be acceptable to parents or effective in producing sustainable improvements.

It is interesting that psychologists are scarcely represented in the FCC literature. In the one paper obtained, Roberts and Magrab (1991) recommended that to use a FCC approach, psychologists should prioritise strengthening families' informal support networks, as parents can see how this is relevant. If psychologists do not gain experience of working as equal partners with service users when conducting research, they might be less likely to use collaborative intervention approaches. Researchers will remain reluctant to use participatory action research due to lack of knowledge and experience about how to work in this way, unless they are trained in these methods (Pullmann, 2009).

The Therapeutic Relationship

All professionals develop a therapeutic relationship with service users. Bella and Mahoney (1998) suggested professionals need support to acquire skills that promote FCC, yet many professionals do not get trained in how to interact with families as partners (Knox, Parmenter, Atkinson & Yazbeck, 2000). In part, this is because such values are not believed to be teachable (Dinnebeil & Hale, 1996). However, Bidmead and Cowley (2005) studied a training course designed to enhance FCC skills in health visitors. After attending the training, health visitors were better listeners, were more open to parents' views, perceived and tackled parents' problems differently and found working with parents more enjoyable. Unfortunately, parents' views were not obtained to corroborate whether these changes were perceived positively. However, if further research suggests that some FCC qualities can be taught, psychologists are well equipped to provide such professional development initiatives.

In terms of clinical practice, Scott and Dadds (2009) summarised that psychologists should be warm, supportive, perceived as being on the families' side, but should also be clear that they can not help unless the family also helps themselves. Roberts and Magrab

(1991) suggested that psychologists needed more opportunities to interact with families during their training, perhaps outside of a clinical context, so that they could develop these collaborative working practices. Recent emphasis on service user involvement with service provision endorses such an approach.

For all professionals, supervision could help sustain FCC practice. Collaborating with families can be anxiety provoking, because professionals' perceive that they have less influence, but feel just as much responsibility. A supervisory relationship that is collaborative and supportive and which models joint decision-making and negotiates power imbalance, is necessary to support this approach. Over time this should ensure that service procedures and processes authentically embody the concepts of FCC.

Conclusion

Despite FCC often being discussed in somewhat idealised terms, it is possible to derive practical applications from its framework that are feasible within service constraints. FCC theory also suggests a future research agenda that recognises the importance of how studies are conducted. This should guide future research, which considers how to improve service contact with families and how to provide acceptable and effective interventions.

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Ethics Protocol

SCHOOL OF PSYCHOLOGY ETHICAL APPROVAL FORM

Please complete all parts to this form.
Please attach consent and information/debriefing sheets to all applications.

Date: JUNE 2010.

Tick one box: ☐ **STAFF PROJECT** ☐ **MASTERS PROJECT** ☐ **PHD PROJECT**

☑ **CLINICAL PSYCHOLOGY PROJECT** ☐ **UNDERGRADUATE PROJECT**

☐ **CLASS DEMONSTRATION**

What is the broad research area? ☐ **Vision and the Brain** ☑ **Clinical & Health**

☐ **Language and Development** ☐ **Other**

Who is the funder of the research?

Title of project: FAMILY-CENTERED CARE-GIVING AND WELL-BEING IN A SPECIALIST CHILDREN'S SERVICE: LINKING PROCESS WITH OUTCOME.

Name and email address(es) of all researcher(s):
GILL TOMS: g.toms@googlemail.com.

Name and email address of supervisor (for student research):
DR HELEN HEALY: h.healy@bangor.ac.uk.

Study Start Date:- 01/09/2010 **Study End Date:-** 01/09/2011

	YES	NO
Is your project in the area of Health and Social Care requiring sponsorship by the University of Wales, Bangor? If yes, please **complete your ethics application in NRES format** and **submit an NHS R&D form** alongside it. **You should still complete all sections to this form, but do not need to supply the additional information requested in boxes A or B of Part 1.**	✓	
Does your project require scrutiny from an outside body that has its own forms? If yes, please **complete your ethics application using the forms required by that outside body. You should still complete all sections to this form, but do not need to supply the additional information requested in boxes A or B of Part 1.**		✓
If a student project, is this part of the supervisor's ongoing research that has been previously reviewed and approved? If yes, please **give the proposal number of the approved research project, and complete all sections of this form.**	Proposal no.	✓

PART ONE: ETHICAL CONSIDERATIONS

		YES	NO	N/A
1	Will you describe the main experimental procedures to participants[1] in advance, so that they are informed about what to expect?	✓		
2	Will you tell participants that their participation is voluntary?	✓		
3	Will you obtain written consent for participation?	✓		
4	If the research is observational, will you ask participants for their consent to being observed?			✓
5	Will you tell participants that they may withdraw from the research at any time and for any reason?	✓		

---

[1] In questions 1-9, if participants are children, please consider the information that you will supply to the legal guardian in each case.

6	With questionnaires, will you give participants the option of omitting questions they do not want to answer?		✓	
7	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	✓		
8	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?	✓		

If you have ticked **No** to any of Q1-8, but have **ticked box A** overleaf, please give an explanation on a separate sheet.
[Note: N/A = not applicable]

		YES	NO	N/A
9	Will your project involve deliberately misleading participants in any way?		✓	
10a	Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort? If **Yes**, give details on a separate sheet and state what you will tell them to do if they should experience any problems (e.g., who they can contact for help)	✓ – Neglible risk. See IRAS FORM FOR DETAILS.		
10b	**Is there any realistic risk of any participants experiencing discomfort or risk to health, subsequent illness or injury that might require medical or psychological treatment as a result of the procedures?**		✓	

If you have ticked **Yes** to 9 or 10 you should normally **tick box B** overleaf; if not, please give a full explanation on a separate sheet.

11	Does your project involve work with animals? If yes, please **tick box B** overleaf.			✓	
12	Does your project involve payment of participants that differs from the standard rates? Is there a significant concern that the levels of payment you offer for this study will unduly influence participants to agree to procedures that they may otherwise find unacceptable? If yes to either, please tick box B and explain in point 5 of the full protocol.			✓	
13	Do participants fall into any of the following special groups? If they do, please refer to BPS guidelines, and **tick box B** overleaf. **Note that you may also need to obtain satisfactory CRB clearance.**	**Children (under 18 years of age)** N.B. You must ensure that you have made adequate provision for child protection issues in your protocol		✓	
		People with learning or communication difficulties N.B. You must ensure that you have provided adequate provision to manage distress		✓	
		Participants covered by the Mental Capacity Act: i.e. Adults over 16 years of age who lack the mental capacity to make specific decisions for themselves. You must ensure that you have appropriate consent procedures in place (See guidance notes below) Some research involving participants who lack capacity will require review by an NHS REC. If you are unsure about whether this applies to your study, please contact the Ethics Administrator in the first instance		✓	

	PARTICIPANTS WILL BE PARENTS AND CARERS USING THE SPECIALIST CHILDRENS SERVICE. →	**Patients** N.B. You must ensure that you have provided adequate provision to manage distress.	✓		
		People in custody		✓	
		People engaged in illegal activities (e.g. drug-taking)		✓	
		Participants recruited from one of the Neurology Patient Panels or the Psychiatry Patient Panel and, if so, has the protocol been reviewed by the appropriate expert/safety panel?		✓	
		Physically vulnerable adults N.B. You must ensure that there is a person trained in CPR and seizure management on hand at all times during testing.		✓	
14 Does your project require use of any of the following facilities **and, if so, has the protocol been reviewed by the appropriate expert/safety panel? If yes, tick Box B overleaf and supply evidence that the appropriate panel have endorsed your study.**		**MRI**		✓	
		TMS		✓	

Mental Capacity Act 2005

The act provides a comprehensive legal framework for decision making adults, aged 16 or over, when, because of specific mental disability (defined as an impairment of or disturbance in the functioning of a person's mind or brain), they lack the mental capacity to make specific decisions for themselves.

The Act enshrines several key principles:

- A person must be assumed to have capacity unless it is established that he/she lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.
- Any decision made under this Act on behalf of a person who lacks capacity must be made in her/his best interests.

Intrusive research on people lacking capacity to consent is unlawful unless:

- The research is approved by specified body (LREC/MREC etc)
- It relates to the person's condition or treatment, and has negligible risks
- It cannot be done as effectively on people who have capacity to consent
- Stringent safeguards are put in place, including consultation with carers.

Researchers conducting studies involving individuals lacking capacity must familiarise themselves with their responsibilities under the law and ensure proper approval mechanisms and appropriate consent procedures are in place.

There is an obligation on the lead researcher to bring to the attention of the School Ethics and Research Governance Committee any ethical implications not clearly covered by the above checklist.

PLEASE TICK **EITHER** BOX A **OR** BOX B OVERLEAF AND **PROVIDE THE DETAILS REQUIRED** IN SUPPORT OF YOUR APPLICATION.

Please tick

A. I consider that this project has **no** significant ethical implications to be brought before the Departmental Ethics Committee.	☐
Give a brief description of participants and procedure, including information on (1) hypotheses, (2) participants & recruitment, (3) research methodology, and (4) Estimated start date and duration of the study. Please attach consent and debrief forms.(5) For studies recruiting via SONA please provide the summary of the study that will appear in SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.	

Please tick

B. I consider that this project **may** have ethical implications that should be brought before the Departmental Ethics Committee, and/or it will be carried out with children or other vulnerable populations. ☐

Please provide all the further information listed below in a separate attachment, in this order.

1. Title of project
2. The potential value of addressing this issue
3. Brief background to the study
4. The hypotheses
5. Participants: recruitment methods, age, gender, exclusion/inclusion criteria
6. Research design
7. Procedures employed
8. Measures employed
9. Qualifications of the investigators to use the measures (Where working with children or vulnerable adults, please include information on investigators' CRB disclosures here.)
10. Venue for investigation
11. Estimated start date and duration of the study (N.B. If you know that the research is likely to continue for more than three years, please indicate this here).
12. Data analysis
13. Potential offence/distress to participants
14. Procedures to ensure confidentiality and data protection
15. *How consent is to be obtained (see BPS Guidelines and ensure consent forms are expressed bilingually where appropriate. The University has its own Welsh translations facilities on extension 2036)
16. Information for participants (provide actual consent forms and information sheets) including if appropriate, the summary of the study that will appear on SONA to inform participants about the study. N.B. This should be a brief factual description of the study and what participants will be required to do.
17. Approval of relevant professionals (e.g., GPs, Consultants, Teachers, parents etc.)
18. Payment to: participants, investigators, departments/institutions
19. Equipment required and its availability
20. If students will be engaged a project involving children, vulnerable adults, one of the neurology patient panels or the psychiatric patient panel, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
21. If students will be engaged in a project involving use of MRI or TMS, specify on a separate sheet the arrangements for training and supervision of students. (See guidance notes)
22. What arrangements are you making to give feedback to participants? The responsibility is yours to provide it, not participants' to request it.
23. Finally, check your proposal conforms to BPS Guidelines on Ethical Standards in research and sign the declaration. If you have any doubts about this, please outline them.

PLEASE COMPLETE PART TWO OVERLEAF.

PART TWO: RISK ASSESSMENT

If you tick "yes" to any of the questions in the table below, please outline on a separate sheet the probability and significance of the risks involved and the means proposed for the management of those risks. **Where relevant, please also describe the procedures to be followed in the event of an adverse event or emergency.**

			YES	NO	N/A
1	Is there significant potential risk to **participants** in any of the following ways?	Potential adverse effects		✓	
		Potential distress **Potential for persisting or subsequent illness or injury that might require medical or psychological treatment**		✓	
2	Is there significant potential risk to **investigator(s)** in any of the following ways?	Potential risk of violence or other harm to the investigator(s) (e.g., through work with particular populations or through context of research).		✓	
		Potential risk of allegations being made against the investigator(s). (e.g., through work with vulnerable populations or context of research).		✓	
3	Is there significant potential risk to the **institution** in any way? (e.g., controversiality or potential for misuse of research findings.)			✓	
4	Is there significant potential risk to other members of staff or students at the institution? (e.g., reception or other staff required to deal with violent or vulnerable populations.)			✓	

The following questions address specific situations that can carry risks to the investigators and/or participants. If you tick "yes" to any of the questions below, please refer to the guidance given (see *Ethics Guidance and Procedures*) on procedures for dealing with these risks and, **on a separate sheet, outline how these risks will be dealt with in your project.**

5	Does the research involve the investigator(s) working under any of the following conditions: alone; away from the School; after-hours; or on weekends?		✓	
6	Does the experimental procedure involve touching participants?		✓	
7	Does the research involve disabled participants or children visiting the School?		✓	

There is an obligation on the lead researcher to bring to the attention of the School Ethics and research Governance Committee any risk implications of the research not clearly covered by the above checklist.

PLEASE COMPLETE PART THREE OVERLEAF.

PART THREE: RESEARCH INSURANCE

The purpose of this section is to decide whether the University requires additional insurance cover for a research project. In the case of student research, this section should be completed by the supervisor.

		YES	NO	N/A
1	Is the research to be conducted in the UK?	✓		
2	Is the research based **solely** upon the following methodologies? ▪ Psychological activity ▪ Questionnaires ▪ Measurements of physiological processes ▪ Venepuncture ▪ Collections of body secretions by non-invasive methods ▪ The administration by mouth of foods or nutrients or variation of diet other than the administration of drugs or other food supplements	✓		

If you have ticked "Yes" to the questions above, then insurance cover is automatic for your research, once your study has been approved by the school Ethics and Research governance Committee and there is no need to do anything further.

If the answer to either of the above questions is "No," we will supply you with a further questionnaire to complete and return to the Insurance Officer; in these cases **the research should not commence until it has been established that appropriate insurance cover is in place. Please request this questionnaire from the Ethics Administrator.**

PLEASE SIGN AND DATE THE DECLARATIONS ON THE FINAL PAGE OF THIS FORM OVERLEAF.

Declaration of ethical compliance
This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Handbook, and that this research will comply with them.

Declaration of risk assessment
The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.

Declaration of conflicts of interest
To my knowledge, there is no conflict of interest on my part in carrying out this research.

Declaration of data ownership and IPR (for students)

I understand that any data produced through this project are owned by the University and must be made available to my supervisor on request or at the end of the project. I confirm that I am aware of the University's Intellectual Property Policy and that this research will comply with it.

For Undergraduate and Masters projects, I understand that in signing this form I am certifying that the study described meets appropriate scientific standards AND that I have reviewed the procedures described to ensure that they comply with ethical guidelines as published by the BPS and described in the School of Psychology's Ethical Guidance Procedures.

(Chief i~~nvestigat~~or/supervisor)

Signed: Helen Healy

Date: 14.06.10

(Associate investigator(s)/student(s)

Signed: Gill Towns.

Date: 14/6/10.

For School Use Only

Reviewer 1 Name…………………………………… Approved Signature……………………Date

Reviewer 2 Name…………………………………… Approved Signature……………………Date

Proposal No. ……………………………………

Subject: Ethics 1626
From: [redacted]
Date: Wed, 28 Jul 2010 16:36:40 +0100
To: [redacted]

Dear Colleagues

Family-centered care giving and well being in a Specialist Childrens service linking process with outcome: Ethics proposal 1626

Your research proposal referred to above has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied:

(i) That the research proposed accords with the relevant ethical guidelines.
(ii) That the research proposed is appropriate for sponsorship by Bangor University.
Approval is granted subject to you submitting Welsh translations of your information/consent and debrief forms to me.

If you wish to make any non-trivial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if research participants experience any unanticipated harm as a result of participating in your research.

You should now forward the application to NRES and to the appropriate Local Research Ethics Committee (LREC). **If you need a signature on the form regarding research sponsorship by the University, and/or a letter confirming this sponsorship, please send the final version of your NRES form to me and I will make arrangements for this.**

The NHS Research Ethics Committee expect one of the investigators to make an oral presentation in support of the proposal at their meeting. You will be contacted by their committee with details as to the date and place of the meeting at which your proposal will be considered.

You may not proceed with the research project until you are notified of the approval of the Local Research Ethics Committee and have R&D approval from the relevant NHS Trusts.

The approval for this project is given on the understanding that you will complete a review form on the project when requested; to this end I would be grateful if you could complete the form below and return it to me.

Yours sincerely

[redacted]

UWB-SPONSORED RESEARCH PROJECTS

MONITORING ARRANGEMENTS FORM

Principal Investigator: ______________________________

Project Title [redacted]

Because Bangor University has agreed to act as research sponsor for the research project named above, we are required to ensure that arrangements are in place to monitor the progress of the project. Please read through the information below, tick the box that applies to this project, and return to the ethics coordinator.

○ **This research is funded by an external agency that requires regular progress reports.**
In this case, please copy all such progress reports to the ethics coordinator for review.

○ **This is student research under your supervision.**
It is the responsibility of the supervisor to monitor the progress of research conducted by students and to report any significant changes or issues arising to the ethics coordinator.

○ **Progress reports are not required for this research by the external funder, or this is non-funded research conducted by you as a staff member.**
The ethics coordinator will contact you at regular intervals for a short progress report.

--
[redacted]
Research and PhD Administrator,
Room 11.3,
School of Psychology
Brigantia Building,
Penrallt Road,
Bangor
LL57 2AS

Tel: 01248 383671
THE LAST DATE FOR PAPER ETHICS SUBMISSIONS IS 30TH AUGUST 2010
THE LINK TO THE ELECTRONIC FORM IS ***https://intranet.psychology.bangor.ac.uk/ethics/***

[redacted]

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Family-centred care-giving: Linking process with outcome in a SCS V1

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial or clinical investigation

● Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

○ Study involving qualitative methods only

○ Study limited to working with human tissue samples, other human biological samples and/or data *(specific project only)*

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	● No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	● No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	● No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England

○ Scotland

● Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ● No

7. Do you plan to include any participants who are adults unable to consent for themselves through physical or mental incapacity? *The guidance notes explain how an adult is defined for this purpose.*

○ Yes ● No

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service in England or Wales?

○ Yes ● No

9. Is the study, or any part of the study, being undertaken as an educational project?

● Yes ○ No

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

● Yes ○ No

10. Is this project financially supported by the United States Department for Health and Human Services?

○ Yes ● No

11. Will identifiable patient data be accessed outside the clinical care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ● No

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study

National Patient Safety Agency
National Research Ethics Service

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Family-centred care-giving: Linking process with outcome in a SCS V1

Please complete these details after you have booked the REC application for review.

REC Name:
North West Wales

REC Reference Number:
10/WNo01/48

Submission date:
09/08/2010

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Family-centred care-giving and well-being in a Specialist Children' Service: Linking process with outcome.

A2-1. Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
Bangor University

Name and contact details of academic supervisor:

	Title	Forename/Initials	Surname
	Dr	Helen	Healy
Address	NWCPP, School of Psychology		
	Bangor University, Bangor		
	Gwynedd		
Post Code	LL57 2DG		

E-mail [redacted]
Telephone
Fax

Name and contact details of student:

	Title	Forename/Initials	Surname
	Miss	Gill R	Toms

Address NWCPP, School of Psychology
Bangor University, Bangor
Gwynedd
Post Code LL57 2DG
E-mail [redacted]
Telephone
Fax

A copy of a current CV for the student (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

● Student
○ Academic supervisor
○ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Gill R	Toms

Post Trainee Clinical Psychologist
Qualifications BSc Psychology
Employer National Health Service/ North Wales Clinical Psychology Programme
Work Address NWCPP, School of Psychology
Bangor University, Bangor
Gwynedd,
Post Code LL57 2DG
Work E-mail [redacted]
* Personal E-mail
Work Telephone
* Personal Telephone/Mobile
Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

Title	Forename/Initials	Surname
Dr	Oliver	Turnbull

Address School of Psychology
Bangor University, Bangor
Gwynedd
Post Code LL57 2DG
E-mail
Telephone
Fax [redacted]

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	
Protocol Version:	2
Protocol Date:	16/07/2010
Funder's reference number:	N/A

International Standard Randomised Controlled Trial Number (ISRCTN): N/A

ClinicalTrials.gov Identifier (NCT number): N/A

European Clinical Trials Database (EudraCT) number: N/A

Project website: N/A

Ref.Number Description	Reference Number
N/A	N/A

A5-2. Is this application linked to a previous study or another current application?

○ Yes ● No

Please give brief details and reference numbers.
N/A

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. This summary will be published on the website of the National Research Ethics Service following the ethical review.*

The study aims to investigate perceptions of family-centred practice in a Specialist Children's Service (SCS) and how these processes of care relate to family and child outcomes.

Aspects of family-centred practice, such as recognising the importance of the family to the child's well-being, have been extensively studied (Matson, Mahan & LoVollu 2009, Hastings, 2002) but there has been no exploration of how family-centred practice relates to child and family outcomes in a SCS. Research suggests that family-well being is particularly relevent when supporting children with learning disabilities. The Incredible Years (IY) parenting course aims to increase family coping skills and so optimise their well-being. This can be considered to be an aspect of providing family-centred practice. However, it is not known if parents of children with learning disabilities perceive the IY course as family-centred. Investigating how family-centred practice is perceived and how it relates to family and child outcomes will assist with service development and more tailored provision in SCS.

Parents who have had contact with the SCS in the last year will be asked to complete questionnaires to ascertain perceptions of family-centred care and outcomes, including: family impact, parental well-being and children's behaviour. This quantitative information will be extended by inviting parents who have attended an IY course facilitated by the SCS to a focus group. This will explore their perceptions of how the course related to family-centred practice.

A6-2. Summary of main issues. *Please summarise the main ethical and design issues arising from the study and say how you have addressed them.*

1. Participants will be busy parents and they will be asked to give their time to the study. The proposed questionnaires have been employed in previous research and the time commitment required to complete them has been balanced with the desire to obtain rich and detailed information.

2. The design of the study ensures that neither participation or lack of participation will alter the service parents receive from the SCS. For instance, parents will have the option of attending the IY course without participating in the study.

3. There are no identified risks associated with parents attending the IY programme or completing questionnaires. However, if parents do become distressed at any point during the study care will be taken to provide adequate support and recommendations. The IY course will be facilitated by professionals aware of procedures for assessing and managing risks and the researcher who will lead the focus group will be familiar with risk management protocols in SCS. The family's case manager will be ascertained when parents consent to participate and case managers will be alerted to any concerns about parental well-being.

4. It is possible that during the focus group it may become apparent that parents are using abusive parenting techniques or parents may disclose abuse. Participants will be reminded of professionals duty of care at the start of the focus group. If any disclosures are made the trust's child protection procedures will be followed and the child's case manager will be informed of any disclosures that impact on child or parent safety.

5. Another study using the IY course found that parents with worse scores on baseline measures (indicating poorer functioning) were more likely to drop out(Baker & Brightman, 1984) suggesting they may be unlikely to contribute to the end of course focus group. In the current study, participants will have volunteered to participate and this should minimise the risk that parents will not have sufficient resources to attend the programme. Parents will not have needed to attend all course sessions to participate in the focus group.

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are parental perceptions of a family-centred practice approach and how do these perceptions relate to measures of family and child functioning?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Do parents using the Specialist Children's Service perceive the IY course to be family-centred and effective in meeting their and their child's needs?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

This project aims to extend the current literature on family-centred practice into a clinical context. Despite family-centred practice being endorsed in government policy since 1991, the Measure of Processes of Care questionnaire, which examines perceptions of family-centred practice, has not been administered to families using a Specialist Children's Service (SCS) to explore how family-centred practice may relate to family and child functioning.

The literature provides evidence that families who use SCS may be at risk of experiencing stress and clinical levels of mental health problems because of caring for their child with learning disabilities (e.g. Tonge, Bereton, Kiomall, Mackinnon, King & Rinehart, 2006). This may relate to the child's often comorbid behaviour problems as well as their developmental delay (e.g. Hastings, 2002). Families' ability to cope can mediate this risk and in this context, therefore, how services are perceived to deliver aspects of family-centred practice may be particularly relevent.

Additionally the study will extend the literature pertaining to the IY course. This course aims to augment families' coping strategies and can be considered to be an aspect of providing family-centred practice. The effectiveness of the IY course for parents whose children have developmental delays has been demonstrated (e.g. McIntyre, 2008). However there has been no qualitative exploration of the IY course's acceptability and perceived usefulness to such parents. This research will consider how and if the IY course can be integrated into a family-centred practice model in a SCS.

A13. Please give a full summary of your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the l person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Previous research suggests that perceptions of family-centred care should correlate to measures of family and child functioning. A mixed methods design has been chosen to explore these factors in a SCS. Quantative analysis will replicate previous studies in the context of a SCS and qualitative information will provide further detail of parental perceptions of family-centred practice. The study has two parts to reflect the mixed methods design but both parts will taken place concurrently.

The SCS has generated a research list of parents who are willing to be contacted about research projects being undertaken in the service. This list contains the parents name, child's name and age and the family's contact details. Parents who have agreed to participate in on going research studies will be contacted in writing and invited to participate in part one of the study. All parents who have accessed the SCS in the last 12 months will be eligible to participate. A range of additional recruitment procedures may be used. Parents may be given questionnaire packs by professionals in the SCS or by the researcher who can be present in SCS waiting rooms during key clinics. Parents can complete the questionnaires at home and mail them back to the service or they can complete questionnaires in SCS waiting rooms. Additionally adverts may be displayed in SCS to recruit additonal parents, with the questionnaire packs being available from SCS receptionists.

Social-demographic information will be collected and parents will be asked to complete the following questionnaires:

- General Health Questionnaire (12 questions)
- Family Impact Questionnaire (50 questions)
- Parent and Family problems sub-scale of the Short Form Questionnaire on Resources and Stress (20 questions)
- Positive Gain Scale (7 questions)
- A visual analogue scale indicating parent's perceptions of the global impact of their child on the family (1 question)
- Child Behaviour Checklist (85 questions)
- Measure of Processes of Care (20 questions)
- Client Satisfaction Questionnaire (8 questions)

Part two hopes to extend the findings of the survey with qualitative information. Parents who have attended a pilot 12 week IY Toddler course facilitated by SCS will be invited to attend a focus group to explore their perceptions of the programme, its family-centred charactersitcs, acceptability and usefulness. Questions for this focus group will be derived partly from the Measure of Processes of Care questionnaire used in part one of the study. The focus group will take place in the same venue as the Incredible Years course to promote attendance. The researcher will not be involved in the running of the parenting course to reduce the possibility of researcher bias.

It will be necessary to obtain some information in part two of the study to characterise the sample and the clinical usefulness of the course to participants. Therefore demographic information about the child and the parent who attended the course will be collected. This will include accessing the child's clinical notes to derive a profile of their developmental abilities. Parents will be asked to complete the following pre and post course measures:

- Strengths and Difficulties Questionnaire (25 questions)
- Parent Defined Problems Questionnaire (3 questions)
- Client Satisifaction Questionnaire (8 questions)

It is anticipated that recruitment will start in September 2010 and data collection should be completed by January 2011.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☐ Design of the research

☐ Management of the research

☐ Undertaking the research
☐ Analysis of results
☐ Dissemination of findings
☑ None of the above

Give details of involvement, or if none please justify the absence of involvement.
Although SCS service users have not been involved in planning or implementing the research, professionals in SCS have been consulted. A primary aim of the study is to enable SCS service users to provide feedback on family-centred practice as they perceive it and in this sense they will be actively involved in the undertaking of the research.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

To complete the questionnaire survey participants must:
- Be the carer of a child who is accessing the Specialist Children's Service
- Have had contact with the Specialist Children's Service in the last 12 months.

To attend the focus group participants must:
- Have children under 6- 7 years old who access the SCS
- Be attending the pilot IY Toddler course facilitated by the SCS

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

In the questionnaire survey the only exclusion criteria is if participants have not accessed the SCS in the last twelve months.

The focus group is for parents/ carers who are attending the pilot IY course. This course is not primarily designed for parents whose child has severe learning disabilities and/ or severe motor or sensory problems. These parents will not be recruited because significant modifications to the IY course would be needed to meet their needs. This is consistent with previous research which has evaluated the IY course with parents of children with learning disabilities (e.g. McIntyre, 2008).

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Part One: Completing Questionnaires	9	0	approx 80 minutes	It is envisaged that most participants will complete the questionnaires at home at a time convenient to them. However some participants may complete the questionnaires in SCS waiting rooms. The researcher will be able to provide assistance if requested.
Part Two: Completing consent form	1	0	approx 5 minutes	With the researcher prior to starting the IY course at an SCS site.

Part Two: Completing Questionnaires pre-course	3	0	approx 20 minutes	With the researcher or with the course facilitators in the first IY session at an SCS site.
Part Two: Completing Questionnaires post-course	3	0	approx 20 minutes	With the reseacher or with the course facilitators in the final IY session at an SCS site
Part Two: Post course focus group	1	0	approx 60 minutes	With the researcher in the same venue as the IY course (an SCS site).

A21. How long do you expect each participant to be in the study in total?

Participants who complete the questionnaire survey will leave the study as soon as their questionnaires are returned. Participants who attend the IY course will be seen pre and post course by the primary researcher. The course lasts twelve weeks and it is envisaged that participants will be in the study for approximately sixteen weeks.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

The main burden to participants in the survey is the time needed to complete the questionnaires. Wherever possible short versions of the questionnaires have been chosen which still facilitate detailed and useful information to be collected. All the questionnaires included have been used in previous research and have adequate psychometrics so the danger of participants misunderstanding the quesitonnaires or having difficulty completing them has been minimised.

The potential benefits of using questionnaires is that parents can complete them at their own convenience. The risk of breaching confidentiality has been minimised as negligible identifiable information is being collected. No previous research has reported that the questionnaires have upset parents but this possibility can not be excluded. The information collected in the Client Satisfaction Questionnaire will additionally help with service evaluation and audit and the addition of this measure has been agreed with the SCS.

Participants invited to the focus group will be asked to complete three short questionnaires before and after the IY course. This will limit the additional burden on them and should not interfere with their attendance of the IY course. Attending the focus group may cause distress to some participants but this is unlikely as the questions will relate to their reflections of the course. Support will be available if participants do become distressed, by referring the participant to their case manager. Case managers will be alerted if the researcher has any concerns about participants safety.

In the focus group more identifiable information will be collected and participants will be aware before they consent to the limits of confidentiality. Collecting more identifiable data is justified because the focus group should provide rich feedback on the IY course. This will help develop the IY course so it is more accessible and useful for parents of children with learning disabilities in the context of SCS's.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

● Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

One of the questionnaires used asks questions about the child's with learning disabilities current behavioural difficulties. Other questionnaires ask about family functioning and parents mental health. No previous research has indicated these questionnaires have caused distress to participants.

During the focus group it may become evident that participants are using abusive parenting techniques. The participant information sheet and consent form will highlight the limits to confidentiality. When consenting to take part, participants will provide the name of their child's case manager and any risks that pertain to parent or child safety will be raised with the appropriate case manager.

A24. What is the potential for benefit to research participants?

The questionnaires ask about family impact, parent and child well-being and perceptions of family-centred practice as well as service satisfaction. This information will assist the SCS to audit its service delivery and plan how to meet the needs of service users. Service development should benefit both current and future service users.

Obtaining qualitative reflections on the IY course should help facilitators refine the course for parents of children with learning disabilities.

A26. What are the potential risks for the researchers themselves? *(if any)*

There are not anticipated risks for researchers in this study. The researcher is a trainee clinical psychologist and will have access to research and clinical supervision during the study. The focus group will hopefully provide a substantial amount of qualitative data which will need to be transcribed and analysed. Three weeks have been allocated to this aspect of data analysis to ensure that reommended working times, especially time spent working on a computer, are adhered to. The contact number provided for the researcher on participant information sheets and on the poster is a mobile number being used only for the study.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Questionnaire survey: The SCS is establishing a list of families who are willing to participate in research. Phase one of recruitment will mail families on this list if they have had contact with the SCS in the last calendar year. Study information, a consent form and questionnaires will be sent to them by the primary researcher and they will be invited to partipate. To recruit further families, SCS professionals will give participant information letters and questionnaire packs to families they see. The researcher will not be informed who these families are. If further participants are required then additional recruitment proedures will be discussed with SCS: these could entail the researcher being available in SS waiting rooms during key clinics to provide families with study information and displaying posters about the study in SCS sites.

Focus group: The SCS will recruit families for the IY course. These parents will be given information about the study by the recruiting professional. If they express an interest they will be contacted by the researcher and will be invited to participate. It is possible that some of these parents will already have participated in the questionnaire survey. Parents will have the option of attending the IY course without participating in the study.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ● No

Please give details below:
Participants who are on the SCS research list (a list of parents willing to be contacted about reseach taking place in the service) will initially be recruited. These families have consented to their name, address and child's age being made available to researchers. Professionals handing out questionnaire packs will not need to disclose any participant information to the researcher.

SCS professionals recruiting families to the IY course will ask them if they wish to participate in the focus group study. Only the details of parents who agree to participate will be forwarded to the researcher.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

● Yes ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material *(with version numbers and dates).*

Depending on the response to initial recruitment efforts, posters about the questionnaire survey may be displayed in SCS sites (which include sites in Caernarfon, Bangor, Anglesey and Pwllheli. Posters will highlight that questionnaire packs (which include a participant information sheet) can be collected from the SCS receptionists and will give contact details for the researcher. As previously stated the mobile contact number is only being used for the study and is not a personal number.

A29. How and by whom will potential participants first be approached?

Participants who are on the SCS research list will be sent out the questionnaire pack including the participant information sheet. Other participants will be given the questionnaire pack by the professional involved in their care. Advertisment posters may be displayed in SCS sites to recruit further participants and the researcher may be available during key clinics in SCS waiting rooms to recruit participants.

Parents recruited for the IY course will be told about the study. If they express an interest the researcher will then contact them with further information.

A30-1. Will you obtain informed consent from or on behalf of research participants?

● Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Questionnaire survey packs will contain a participant information sheet and consent form and respondents will be asked to sign the consent form as well as completing the questionnaires. Participants in the focus group will be asked to sign a consent form to indicate which aspects of the study they agree to partake in. Both participant information sheets will include contact details of the researcher and the research supervisor should participants have any questions or concerns.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

● Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be asked to return the questionnaire packs by 31st December 2010 if they wish to participate. If participants are given the questionnaires by the researcher, they will have the options of completing them at the SCS site or taking them home to complete and post back to the service.

Participants provided with information about the focus group will receive initial study information from the SCS professional recruiting them to the IY course. If the family expresses interest in participating, the researcher will contact them to provide further information. They will have until the first IY session to decide whether or not to take part. This is envisaged to be at least a week and during this time they will be able to contact the researcher if they have any questions or concerns.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

The researcher will be available to assist participants to complete questionnaire measures at SCS sites if requested.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision information to participants in Wales?

Participant information letters and consent forms will be translated into Welsh but this will not be possible for the questionnaire measures as these have been standardised in English and no Welsh language versions are available. The Welsh version of the participant information letters will apologise that Welsh versions of the questionnaires are not available.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

● The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

Further details:

In the questionnaire survey no identifiable data will be stored for any participant. Once participants have returned the questionnaires they will have finished participating in the study.

During the IY course participants who lose capacity to consent will be withdrawn from the study and will not be invited to the focus group. Any data already provided, which does not contain identifiable information, will be retained.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

- ☑ Access to medical records by those outside the direct healthcare team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
  - ☐ Manual files including X-rays
  - ☐ NHS computers
  - ☐ Home or other personal computers
  - ☐ University computers
  - ☐ Private company computers
  - ☑ Laptop computers

Further details:

1. Participants attending the IY course and focus group will be asked if their child's SCS file can be reviewed to obtain a developmental profile. This profile is expected to be a Griffith's Assessment and this should be available for most SCS children.

2. The only personal addresses accessed will be those on the research list compiled by the SCS. Parents have consented to these details being made available to researchers.

3. Any direct quotes taken from the focus group will be anonnymised and the consent form will ask for permission to use quotations from the group.

4. The focus group will be audio recorded and the consent form identifies this. Once the information has been transcribed (with identifiers omitted) then the audio data will be destroyed. Video footage may be taken during some IY sessions. This will be done to monitor adherence and fidelity to the course and to assist with the supervision of the course facilitators. No direct use of the video data will be made by the researcher and video data will be destroyed once course facilitators have used it for supervision purposes.

5. Only annonymised data (that can not be traced to individual participants) will be stored on computer file. In the IY course participants will be assigned a number so pre and post measures can be compared. The list matching participants to a random numbers will be stored in a locked cabinet in the SCS (Child Development Centre site).

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Returned questionnaires and audiotape data will be kept in a locked cabinet in the SCS Child Development Centre site. Only the researcher and research supervisor will have access to this data. It is envisaged that raw data will be destroyed in September 2011 when the study is completed and has been graded. Only anonymised information will be stored on computer file.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

No individuals outside the families' care team will have access to participants personal data. Information provided to the researcher during the IY course and focus group will only be shared with the families' case manager if risks to the parent or child are identified. The limits of confidentiality are explained in the relevant version of the participant information sheet and consent form. Alerting case managers to such disclosures would be in accordance with the All Wales Safeguarding Children policy.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

● Less than 3 months
○ 3 – 6 months
○ 6 – 12 months
○ 12 months – 3 years
○ Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

● Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants in the questionnaire survey will be supplied with a postage paid envelope to return questionnaires to the researcher.

Participants in the focus group will have travel expenses refunded for the focus group and any sessions needed before or after the IY course to complete pre and post measures. Travel will be refunded at ten pence per per mile in accordance with local NHS policy. At the focus group light refreshments will be provided (tea, coffee, squash and biscuits etc).

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ● No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ● No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

● Yes ○ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

● Yes ○ No

It should be made clear in the participant's information sheet if the GP/health professional will be informed.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ● No

Please give details, or justify if not registering the research.
The project does not involve running clinical trials and is a doctoral level study.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☐ Conference presentation
☐ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

☐ No plans to report or disseminate the results

☐ Other (please specify)

A53. Will you inform participants of the results?

● Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Focus group participants will receive a written summary of the study. An internal report will be provided to the SCS and will be made available in SCS reception areas as noted on the participant information sheet. This will disseminate the study results to participants who completed the questionnaire survey who can not be sent individual feedback letters because their details will not be known by the researcher.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

☐ Independent external review

☐ Review within a company

☐ Review within a multi-centre research group

☑ Review within the Chief Investigator's institution or host organisation

☐ Review within the research team

☑ Review by educational supervisor

☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The study has been approved by the School of Psychology ethics committee.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed? *Tick as appropriate:*

☐ Review by independent statistician commissioned by funder or sponsor

☐ Other review by independent statistician

☐ Review by company statistician

☐ Review by a statistician within the Chief Investigator's institution

☐ Review by a statistician within the research team or multi-centre group

☑ Review by educational supervisor

☑ Other review by individual with relevant statistical expertise

☐ No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

	Title	Forename/Initials	Surname
	Dr	[redacted]	[redacted]
Department	North Wales Clinical Psychology Programme		
Institution	Bangor University		

Work Address 43 College Road
Bangor
Gwynedd
Post Code LL57 2DG
Telephone [redacted]
Fax
Mobile
E-mail [redacted]

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The primary outcome of interest is the association between perceptions of family-centred practice and family and child functioning. In the questionnaire survey this will be measured by correlating the Measure of Processes of Care questionnaire with the other questionnaire measures which assess family impact, parent, family and child functioning and service satisfaction. The focus group will extend this exploration by considering the themes that arise in the discussion and how these relate to aspects of family-centred care.

A58. What are the secondary outcome measures? *(if any)*

If sufficient survey data are collected potential mediating and moderating factors will be explored.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size:	400
Total international sample size (including UK):	400
Total in European Economic Area:	0

Further details:
The potential sample for the questionnaire survey is estimated to be approximately 400- 500 and a 30% response rate is anticipated. It is planned to send out questionnaires to 200 families as this is feasible within the study's budget and time-frame and should result in the study having sufficient statistical power.

All families (expected to be 10-12 individuals) partaking in the IY course will be invited to participate in the focus group and complete the pre and post questionnaires.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

Studies which have used the same principal measure as this study (the Measure of Processes of Care) in similar populations have found a range of effect sizes. The averaged effect size is moderate and although some effect sizes have been small, others have been large. Therefore, calculating statistical power using a moderate effect size seems justified and a sample of 85 would be sufficient to power the study at a statistical significance level of 0.05. This should be possible by canvassing 200 families selected primarily through the SCS research list.

A61. Will participants be allocated to groups at random?

○ Yes ● No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Analysis of the questionnaire survey will be descriptive and correlational. Descriptive statistics will be generated and Pearson correlation coefficients will be used to explore the relationship between perceptions of family-centred care

Address NWCPP, School of Psychology
Bangor University, Bangor
Gwynedd
Post Code LL57 2DG
Work Email [redacted]
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2010
Planned end date: 01/09/2011
Total duration:
Years: 1 Months: 0 Days: 0

A71-1. Is this study?

● Single centre
○ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
○ Yes ● No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☐ NHS organisations in England
☑ NHS organisations in Wales 1
☐ NHS organisations in Scotland
☐ HSC organisations in Northern Ireland
☐ GP practices in England
☐ GP practices in Wales
☐ GP practices in Scotland
☐ GP practices in Northern Ireland
☐ Social care organisations
☐ Phase 1 trial units
☐ Prison establishments

and the other variables assessed. If sufficient data is collected potential mediators and moderators will be explored through further correlational analysis.

Although there will be a pre and post course comparison of the IY course (using descriptive statistics) the primary focus will be on collecting and analysing qualitative feedback of parents' perceptions of the course as these relate to family-centred care. To analyse the transcript of the focus group the techniques of Framework Analysis (Ritchie & Spencer, 2002) will be employed:

Familisaration: The transcript will be read and recurrent themes and key ideas will be listed. Additional reflections on the data collection process will be noted.

Identifying a thematic framework: A framework to summarise the data will be constructed from the research question, which aims to find out parents' perceptions of family-centered practices and their views of the acceptability of the IY group. The framework will also be guided by emergent issues in the data and analytical themes found in the patterns and recurrences of particular views. It is likely that the framework will initially be quite descriptive and based on the research question but should become influenced more by emerging themes as analysis proceeds.

Indexing: From the thematic framework an index will be created which lists the ideas evident in the data. This index will be used to label the transcript so information can be easily retrieved. Sections of the transcript are likely to be labelled with multiple index items and this will highlight how ideas are associated. It will enable patterns to emerge and the context index items arise in will be evident.

Charting: This is a means of distilling the transcript information. A chart will be created of the main themes and their sub-components. What each focus group participant said in relation to this theme will be summarised in the table with a reference back to the original transcript. Representative quotes will also be referenced for each theme.

Mapping and interpretation: The research question concerns exploring the nature of participants' experience in the IY course. In the final stage of analysis an overall picture will be gained from the data. Participants perceptions will be compared and contrasted and patterns and connections will be highlighted. This will result in key themes being summarised. These themes and example quotations will be discussed in supervision to ensure the analysis has an audit trail. As some simple pre and post measures are being employed this will also enable the focus group information to be compared to another source of course evaluation data to help establish the informations reliability.

Dr Jaci Huws (Bangor University) has agreed to provide informal support and guidance to assist the researcher to undertake the qualitative analysis.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname Dr Helen Healy
Post	Clinical Psychologist
Qualifications	BSc Psychology, PHD Psychology, Dclin Psychology (Bangor University)
Employer	Betsi Cadwaldar University Health Board
Work Address	NWCP, School of Psychology Bangor University, 43 College Road Bangor, Gwynedd
Post Code	LL57 2DG
Telephone	[redacted]
Fax	
Mobile	
Work Email	[redacted]

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
○ NHS or HSC care organisation
● Academic
○ Pharmaceutical industry
○ Medical device industry
○ Local Authority
○ Other social care provider (including voluntary sector or private organisation)
○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Bangor University
Given name	Oliver
Family name	Turnbull
Address	School of Psychology, Bangor University
Town/city	Bangor, Gwynedd
Post code	LL572DG
Country	UNITED KINGDOM
Telephone	[redacted]
Fax	
E-mail	[redacted]

Is the sponsor based outside the UK?
○ Yes ● No

Where the lead sponsor is not established within the UK, a legal representative in the UK may need to be appointed. Please consult the guidance notes.

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ● No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	Dr	Helen	Healy

Organisation Specialist Children's Service/ North Wales Clinical Psychology Programme

☐ Probation areas
☐ Independent hospitals
☐ Educational establishments
☐ Independent research units
☐ Other (give details)

Total UK sites in study: 1

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor University are insuring the study. Please see enclosed document.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☑ Other insurance or indemnity arrangements will apply (give details below)

Bangor university as above.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

All participants will be recruited from the SCS which is an NHS service.

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	[redacted]	Title	Miss
Department name	Specialist Children's Service and all of its clinics	First name/ Initials	Gill
Street address	[redacted]	Surname	Toms
Town/city	[redacted]		
Post Code	[redacted]		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the main REC or the GTAC (as applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the main REC, in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs.
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

☑ Chief Investigator

☐ Sponsor

☐ Study co-ordinator

☐ Student

☐ Other – please give details

☐ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: Gill Toms

Print Name: Gill Toms

Date: 5/8/10. *(dd/mm/yyyy)*

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: Val Morrison

Print Name: ~~Professor Oliver Turnbull~~ DR VAL MORRISON

Post: ~~Head of School, School of Psychology~~ Deputy Head of School

Organisation: Bangor University

Date: 4/8/10 *(dd/mm/yyyy)*

D3. Declaration for student projects by academic supervisor

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific conteni of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the Chief Investigator and the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying th Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Signature: Helen Healy

Print Name: Dr Helen Healy

Post: Clinical Psychologist/ Academic Tutor

Organisation: Betsi Cadwalader NHS Trust/ Bangor University

Date: 05/08/2010 *(dd/mm/yyyy)*

26th September 2010

Dear Mr Owen,

Re: REC reference number: 10/WNo01/48

Thank-you for considering my proposal and for your helpful feedback. Please find below how I have addressed the points you raised and I enclose amended supporting documents.

Point 1.1: The information sheet should include an explanation of how and when data and audiotapes will be destroyed.

On the 'Participant Information Sheet: Questionnaire Survey' the section entitled 'What will it involve?' now finishes with the sentence: 'All raw data will be shredded at the end of the research (September 2011).

On the 'Participant Information Sheet: Focus Group' the section entitled 'What will it involve?' now finishes with the sentences: 'Once the tape has been transcribed, all data files will be deleted. All raw written data will be shredded at the end of the research (September 2011).

Point 1.2: The information sheets and consent forms should be printed on headed paper.

Please find re-submitted letters to participants and consent forms on North Wales Clinical Psychology Programme headed paper.

Point 1.3: The consent form should provide a space for the printed name of the person giving consent

Both consent forms now include a line requesting 'Name (please print)' with space to respond. This is placed below the space for participants to sign their names.

Point 2.1: An explanation should be provided on the relevance of the 'Child Behaviour Checklist' and its correlation to other measures

The Child Behaviour Checklist (CBCL) is being used in the questionnaire survey. This part of the research aims to investigate how caregivers' perceptions of family-centred practice relate to their mood/ well-being, the family's functioning and their child's functioning. The CBCL was chosen as a measure of child functioning.

The CBCL is a well-used measure of child emotional and behavioural difficulties. It was decided to focus on this aspect of child functioning because children using specialist services often have behaviour that caregiver's find challenging and these behaviours cause parents significant distress (Hastings, 2002). Previous research indicates that child behaviour has a significant impact on parental well-being so it will be important to include a measure of child behaviour when conducting correlations between perceptions of family-centred practice and parent and family functioning. Otherwise a significant potential moderator/ mediator will not be explored.

The CBCL has good psychometric properties and is widely used. It has good construct validity, test retest reliability and reported internal consistency ranging from 0.52-0.84. The CBCL covers a wide range of factors encompassing children's functioning (emotionally reactive, anxious/ depressed, somatic complaints, withdrawn, attention problems, aggressive behaviour and sleep problems). The other measures reviewed did not elicit the same amount of detailed information. It is hoped that this detailed information will be informative in terms of exploring correlations between the measures.

I hope I have provided necessary clarification on the points that were raised. Please let me know if you require any further information or clarification.

Yours Sincerely,

Gill Toms	Dr Helen Healy
Primary Researcher	Research Supervisor

NHS
Pwyllgor Moeseg Ymchwil Gogledd Cymru (Y Orllewin)
North Wales Research Ethics Committee (West)

PRIVATE & CONFIDENTIAL
Miss Gill R Toms
NWCPP, School of Psychology
Bangor University, Bangor
Gwynedd
LL57 2DG

Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk

26 August 2010

Dear Miss Toms,

Study Title: **Family-centred care-giving and well-being in a Specialist Children' Service: Linking process with outcome.**
REC reference number: **10/WNo01/48**

Thank you for your letter of 26 August 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
REC application 53601/139789/1/1161		09 August 2010
Response to request for further information	No version	26 September 2010
Protocol	1	05 August 2010
~~Participant Information Sheet: questionnaire~~ superseded	~~2~~	~~16 July 2010~~
Participant Information Sheet: questionnaire	3	24 August 2010
~~Participant Information Sheet: focus group~~ superseded	~~2~~	~~16 July 2010~~
Participant Information Sheet: focus group	3	24 August 2010
~~Participant Consent Form: questionnaire~~ superseded	~~2~~	~~16 July 2010~~
Participant Consent Form: questionnaire	3	20 August 2010
~~Participant Consent Form: focus group~~ superseded	~~2~~	~~16 July 2010~~
Participant Consent Form: focus group	3	20 August 2010
GP/Consultant Information Sheets: letter to case manager	1	10 June 2010
Advertisement: Poster	1	10 June 2010
Questionnaire: MPOC-20	No version	No date
Questionnaire: SDQ 3-4 years	No version	No date
Questionnaire: SDQ 4-16 years	No version	No date
Questionnaire: Client Satisfaction Questionnaire	No version	No date
Questionnaire: Measure of Global Impact on Family	No version	No date
Questionnaire: Family Impact Questionnaire	No version	No date
Questionnaire: CBL 1.5-5 years	No version	No date
Questionnaire: CBL 6-18 years	No version	No date
Questionnaire: Pre-course Measure of Parents' Aims	No version	No date
Questionnaire: Post-course Measure of Parents' Aims	No version	No date
Questionnaire: Positive Gain Scale	No version	No date
Questionnaire: Parent and Family Problems Scale	No version	No date
Questionnaire: 12 item GHQ	No version	No date
Questionnaire: Social Demographic Questionnaire	No version	No date
Investigator CV	No version	05 August 2010
Supervisor CV	No version	No date
Letter from Sponsor	No version	28 July 2010
Evidence of insurance or indemnity	UMAL	31 August 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WNo01/48	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Mr David Owen
Chairman

Email: rossela.roberts@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Sponsor: Prof Oliver Turnbull, Bangor University*
R&D office for Betsi Cadwaladr University Health Board (West)

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D – Y Gorl
R&D Internal Review Panel – West Div

Ysbyty G
Clinical Academi
North Wales Clinical
Bangor, G
LL5

Telephone/Facsimile: 01248 - 3
Email: Rossela.Roberts@nww-tr.wales.

PRIVATE & CONFIDENTIAL
Miss Gill Toms
PhD Student
School of Psychology
Brigantia Building, Penrallt Road
Bangor, Gwynedd
LL57 2PW

6 September 201

Dear Miss Toms,

Re: Review of project

Toms 10/48	Family-centred care-giving and wellbeing in a Specialist Childrer Service: Linking process with outcome
Chief Investigator:	Mrs. Gill Toms
Sponsor:	School of Psychology, Bangor University

The above research project was reviewed at the meeting of the Internal Review Panel held on 2 September 2010.

Documents reviewed:	Version	Date
P & PL Letter	-	01/08/2010
PI Letter	-	01/08/2010
Case Manager's Letter	1.0	10/06/2010
Checklist	1.0	09/08/2010
Measures of Processes	-	09/08/2010
Helen Healy CV	-	09/08/2010
CV of CI (Mrs G Toms)	-	09/08/2010
NHS R&D Form – 53601/139792/14/821	1.0	09/08/2010
Participant Poster	1.0	10/06/2010
Child Behavior Checklist (1½ - 5)	-	-
REC Form - 53601/139789/1/161	1.0	09/08/2010
Child Behavior Checklist (6 – 18)	-	-
Large Scale Research Project Proposal	-	-
Consent Form 1	2.0	16/07/2010
Consent Form 2	2.0	16/07/2010
Participant Information Sheet – Questionnaire	2.0	16/07/2010
Participant Information Sheet – Focus Group	2.0	16/07/2010

The Committee is satisfied with the scientific validity of the project, the risk assessment, the review of the cost and resource implications and all other research management issues pertaining to the application.

I have pleasure in confirming that the Internal Review Panel is pleased to grant approval to proceed at this site (BCUHB – West Division)

GIG CYMRU
NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D – Y Gorlle
R&D Internal Review Panel – West Divis

Ysbyty Gwy
Clinical Academic C
North Wales Clinical Sc
Bangor, Gwy
LL57

Telephone/Facsimile: 01248 - 384
Email: Rossela.Roberts@nww-tr.wales.nh

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval - favourable opinion.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research at this site.

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009).
An electronic link to this document is provided on the R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely

Rossela Roberts

pp Professor David Healy
Consultant Psychiatrist, Professor of Psychological Medicine
Chairman Internal Review Panel

Application for Ethical Approval

Project Title: Family-centered care-giving and well-being in a Specialist Children's Service: Linking process with outcome.

Principal investigator: Toms, Gillian Ruth

Application number: 1626-A1127

Project Title: Family-centered care-giving and well-being in a Specialist Children's Service: Linking process with outcome.

Principal Investigator: [redacted]y Start Date: 01 Oct 2010 Study End Date: 01 Sep 2011
Other Researchers: dit)

Nature of Amendment: I would like to broaden the recruitment procedure to include ethical approval to approach parents in settings other than the key clinics specified in the original proposal.

Ethical approval in the original proposal was received for the following recruitment procedures:

1. Using a research list of parents generated by the Specialist Children's Service (SCS) who are willing to be contacted about current research projects

2. Parents attending key clinics would be given questionnaire packs either by the relevant professional or by the named researcher

3. Posters about the research would be displayed at SCS sites

These approaches have been unsuccessful and the response rate has been extremely poor.

The aim of this amendment is to expand the recruitment beyond key clinics to sessions where parents attend support groups, nursing led educational groups, social skill groups and advocacy settings.

The supporting document attached shows the relevant sections of the original recruitment protocol (as submitted to Bangor University and the NHS) and highlights the proposed additions.

Amendment form

Participants' ability to give informed, voluntary consent
No

Participants' ability to voluntarily withdraw from the research
No

In questionnaire-based studies, participants' option to omit questions
No

Maintenance of confidentiality of participant data
No

The ability to give a full participant debriefing
No

Risks to participants, investigators, or the institution
No

Do you intend to use additional questionnaires, please attach copies with supporting documents.
No

Does the nature of your request entails changes to consent/debriefing information, please attach the amended documents with supporting documents.
No

Amendment declaration

Declaration of ethical compliance: This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures determined by the School of Psychology at Bangor. I understand that I am responsible for the ethical conduct of the research. I confirm that I am aware of the requirements of the Data Protection Act and the University's Data Protection Handbook, and that this research will comply with them.
Yes

Declaration of risk assessment: The potential risks to the investigator(s) for this research project have been fully reviewed and discussed. As an investigator, I understand that I am responsible for managing my safety and that of participants throughout this research. I will immediately report any adverse events that occur as a consequence of this research.
Yes

Declaration of conflicts of interest: To my knowledge, there is no conflict of interest on my part in carrying out this research.
Yes

Declaration of data ownership and IPR (for students): I understand that any data produced through this project are owned by the University and must be made available to my supervisor on request or at the end of the project. I confirm that I am aware of the University¿s Intellectual Property Policy and that this research will comply with it.
Yes

Project Title: Family-centered care-giving and well-being in a Specialist Children's Service (SCS): Linking process with outcome

Notice of amendment: Supporting document – details of changes to extend recruitment procedure included with original protocol

Requested amendments:
Due to an extremely low response rate in the questionnaire survey part of the research, I would like to broaden the recruitment procedure to include ethical approval to approach parents in settings other than the key clinics specified in the original proposal.

Revision to recruitment protocol:
To make the additions very clear, the relevant sections of the NRES ethics form that relate to recruitment for the questionnaire survey are detailed below. Additions to the original protocol text are in bold. Apart from the additions no other changes have been made to the original protocol.

Protocol Item A13:
The SCS has generated a research list of parents who are willing to be contacted about research projects being undertaken in the service. This list contains the parents name, child's name and age and the family's contact details. Parents who have agreed to participate in on-going research studies will be contacted in writing and invited to participate in part one of the study. All parents who have accessed the SCS in the last 12 months will be eligible to participate. A range of additional recruitment procedures may be used. Parents may be given questionnaire packs by professionals in the SCS or by the researcher who can be present in SCS waiting rooms during key clinics. Parents can complete the questionnaires at home and mail them back to the service or they can complete questionnaires in SCS waiting rooms. Additionally adverts may be displayed in SCS to recruit additional parents, with the questionnaire packs being available from SCS receptionists. **Parents will also be approached when they attend support groups, nursing led educational groups, social skill groups and advocacy settings.**

Protocol item A27.1:
Questionnaire survey: The SCS is establishing a list of families who are willing to participate in research. Phase one of recruitment will mail families on this list if they have had contact with the SCS in the last calendar year Study information, a consent from and questionnaires will be sent to them by the primary researcher and they will be invited to participate. To recruit further families, SCS professionals will give participant information letters and questionnaire packs to families they see. The researcher will not be informed who thee families are. If further participants are required then additional recruitment procedures will be discussed with SCS: These could entail the researcher being available in SCS waiting rooms during key clinics to provide families with study information and displaying posters about the study in SCS sites. **Parents may also be recruited from other suitable clinics, groups, parent group meeting and third sector providers.**

Protocol item A29

Participants who are on the SCS research list will be sent out the questionnaire pack including the participant information sheet. Other participants will be given the questionnaire pack by the professional involved in their care. Advertisement posters may be displayed in SCS sites to recruit further participants and the researcher may be available during key clinics in SCS waiting rooms to recruit participants. **As above.**

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Fwd: Ethics Application Approved for [redacted] Inbox X

[redacted]

-------- Original Message --------
Subject: Ethics Application Approved for psp87c
Date: Mon, 31 Jan 2011 11:28:48 -0000
From: Bangor Research Applications [redacted]
To: [redacted]

Dear [redacted]

1626-A1127 Amendment to Family-centered care-giving and well-being in a

Your research proposal number 1626-A1127 has been reviewed by the Schoo
ethical and governance approval for the above research on the basis des
for a maximum of five years from this date.

Ethical approval is granted for the study as it was explicitly described

If you wish to make any non-trivial modifications to the research projec
documents reviewed which have been altered as a result of the amendment.
harm as a result of taking part in your research, or if any adverse reac
.

Governance approval is granted for the study as it was explicitly descri
University's indemnity policy.

If any new researchers join the study, or any changes are made to the wa
submit an amendment form to the committee.

Yours sincerely

[redacted]

--

Reply Reply to all Forward

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Family-centred care-giving: Linking process with outcome in a SCS V1

1. Is your project research?

● Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial or clinical investigation

● Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

○ Study involving qualitative methods only

○ Study limited to working with human tissue samples, other human biological samples and/or data *(specific project only)*

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	○ Yes	● No
b) Will you be taking new human tissue samples (or other human biological samples)?	○ Yes	● No
c) Will you be using existing human tissue samples (or other human biological samples)?	○ Yes	● No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☐ England
☐ Scotland
☑ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England

○ Scotland

● Wales
○ Northern Ireland
○ This study does not involve the NHS

4. Which review bodies are you applying to?

☑ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

5. Will any research sites in this study be NHS organisations?

● Yes ○ No

6. Do you plan to include any participants who are children?

○ Yes ● No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ● No

Answer Yes if you plan to recruit participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ● No

9. Is the study, or any part of the study, being undertaken as an educational project?

● Yes ○ No

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

● Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ● No

11. Will identifiable patient data be accessed outside the clinical care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ● No

Document submitted which lists the changes and gives previous and revised text to the REC form.

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

○ Yes ● No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Is this a modified version of an amendment previously notified and not approved?

● Yes ○ No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.
If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.
If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

Additional information has been provided, as requested in the review of the original amendment (AM01). I would like to broaden the recruitment procedure so it can include ethical approval to approach parents who use the Specialist Children's Service (SCS) in settings other than the key clinics specified in the original proposal.

The aim of this amendment is to expand recruitment beyond key clinics to the following two groups/meetings. Preliminary permission to attend these groups/ meetings has already been obtained from each session coordinator, but will be confirmed before the researcher attends.

Group/Meeting One:
Nursing led educational groups are run at regular intervals by the SCS community nursing staff for parents who use the SCS. The aim of these groups is to provide advice and strategies on the following topics:

- Sleep routines
- Toileting
- Behaviour management
- Play skills

These groups are usually held at SCS clinic sites, such as Alltwen and Ysgol Y Graig in Llangefni.

Group/Meeting Two:
The parent support group also runs on a regular basis. It is organised and facilitated by the Carers Outreach Organisation. The local facilitator is Gwyneth Roberts (Field Officer). The group aims to provide support to parents who have children with Special Needs. Sometimes the meetings have speakers but other meetings provide social events. Meetings are held in community locations, including Ysgol Hafod Lon (which is a school for children with special educational needs).

The researcher would like to attend the groups/ meetings detailed above to inform parents of the research study. Interested parents would have the option of taking a questionnaire pack home or completing it during the group/ meeting, if they wanted assistance from the researcher. This would be the same procedure as agreed in the original protocol. Professionals facilitating these groups/ meetings have agreed the researcher can be present for this purpose and the researchers presence will not impact on the running of the groups.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

N/A

List of enclosed documents

Document	*Version*	*Date*
Notice of amendment- Supporting document	2	18/02/2011

Declaration by Chief Investigator

1. *I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
2. *I confirm that the study sponsor has been notified of the proposed amendment.*
3. *I consider that it would be reasonable for the proposed amendment to be implemented.*

Date:......................................

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SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL
BANGOR
UNIVERSITY

22nd February 2011

Dear Ethics Committee,

Re: Study Title; Family-centred care-giving and well-being in a Specialist Children's Service: Linking process with outcome
REC reference; 10/WNo01/48
Previous amendment number: AM01

Thank-you for your feedback on the amendment to the above study. I am sorry that sufficient information was not included and have clarified the information on the Notice of Substantial Amendment form and the supporting document listing the changes to the protocol, which are included with this letter.

Following your feedback and further discussions we would like ethical approval to meet with two groups/ meetings:

1. A nursing-led education group run by Specialist Children's Services (SCS) community nurses for parents who are in contact with SCS. These groups are run at SCS clinic sites on a regular basis. The attached documentation provides more information as to the locations and purposes of these groups.

2. A parent support group, which is organized and facilitated by the Carers Outreach Organization, meets on a regular basis. It provides support to parents whose children have special needs. These meetings are held in community locations, including Ysgol Hafod Lon, which is a school for children with special educational needs. The purpose of these meetings is described further in the attached documents.

The researcher would like to attend these two groups/ meetings to inform parents of the research study. Interested parents would have the option of taking a questionnaire pack home or completing it during the group/ meeting. Professionals facilitating these groups/ meetings have agreed the researcher can be present for this purpose and the researchers presence will not impact on the running of the groups.

Thank-you for considering this amendment again and we would be happy to provide further information if this is required.

Yours Sincerely,

Gill Toms	Dr Helen Healy
Trainee Clinical Psychologist	Clinical Psychologist
Primary Researcher	Research Supervisor

Project Title: Family-centered care-giving and well-being in a Specialist Children's Service (SCS): Linking process with outcome

Notice of amendment (version 2): Supporting document – details of changes to extend recruitment procedure included with original protocol

Requested amendments:
Due to an extremely low response rate in the questionnaire survey part of the research, I would like to broaden the recruitment procedure to include ethical approval to approach parents who use the SCS in settings other than the key clinics specified in the original proposal.

Revision to recruitment protocol:
To make the additions very clear, the relevant sections of the NRES ethics form that relate to recruitment for the questionnaire survey are detailed below. Additions to the original protocol text are in bold. Apart from the additions no other changes have been made to the original protocol.

Protocol Item A13:
The SCS has generated a research list of parents who are willing to be contacted about research projects being undertaken in the service. This list contains the parents name, child's name and age and the family's contact details. Parents who have agreed to participate in on-going research studies will be contacted in writing and invited to participate in part one of the study. All parents who have accessed the SCS in the last 12 months will be eligible to participate. A range of additional recruitment procedures may be used. Parents may be given questionnaire packs by professionals in the SCS or by the researcher who can be present in SCS waiting rooms during key clinics. Parents can complete the questionnaires at home and mail them back to the service or they can complete questionnaires in SCS waiting rooms. Additionally adverts may be displayed in SCS to recruit additional parents, with the questionnaire packs being available from SCS receptionists. **SCS run nursing-led education groups (covering toileting, play skills, sleep routines, behaviour management, etc) on a regular basis. Similarly, parent support groups are facilitated regularly by the Carers Outreach Organisation for parents whose children have special needs. We will approach parents who attend these two groups/ meetings and inform them about the study. Parents who would like to participate and who meet the study *inclusion* criteria (have had contact with SCS in the last year) will have the option of taking a questionnaire pack or completing it during the group/ meeting with the researcher.**

Protocol item A27.1:
Questionnaire survey: The SCS is establishing a list of families who are willing to participate in research. Phase one of recruitment will mail families on this list if they have had contact with the SCS in the last calendar year Study information, a consent from and questionnaires will be sent to them by the primary researcher and they will be invited to participate. To recruit further families, SCS professionals will give participant information letters and questionnaire packs to families they see. The researcher will not be informed who thee families are. If further participants are required then additional recruitment procedures will be discussed with SCS: These could entail the researcher being available in SCS waiting rooms during key clinics to

provide families with study information and displaying posters about the study in SCS sites. **Parents will also be recruited from the two groups/ meetings as outlined above in A13.**

Protocol item A29

Participants who are on the SCS research list will be sent out the questionnaire pack including the participant information sheet. Other participants will be given the questionnaire pack by the professional involved in their care. Advertisement posters may be displayed in SCS sites to recruit further participants and the researcher may be available during key clinics in SCS waiting rooms to recruit participants. **Addition as detailed above in A27.1.**

North Wales Research Ethics Committee - West
Bangor
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor
Gwynedd
LL57 2PW
Tel/Fax: 01248 -384.877

Miss Gill R Toms
NWCPP, School of Psychology
Bangor University, Bangor
Gwynedd
LL57 2DG

18 March 2011

Dear Miss Toms,

Study title: **Family-centred care-giving and well-being in a Specialist Children' Service: Linking process with outcome.**
REC reference: **10/WNo01/48**
Amendment number: **AM01/1**
Amendment date: **18 February 2011**

Thank you for submitting the above amendment, which was received on 08 March 2011. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 21/02/2011, re: AM01 dated 06/12/2010)

The modified amendment was reviewed at the meeting of the Sub-Committee held on 17 March 2011. A list of the members who took part in the review is attached.

Ethical opinion

Favourable Opinion - I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Covering Letter		22 February 2011
Modified Amendment	AM01/1	18 February 2011
Supporting document - details of changes to the protocol		

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/WNo01/48: Please quote this number on all correspondence

Yours sincerely

Rossela Roberts

Dr Rossela Roberts
Committee Co-ordinator

E-mail: rossela.roberts@wales.nhs.uk

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Sponsor: Prof Oliver Turnbull, Bangor University* *R&D office for BCUHB - West*

North West Wales Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 17 March 2011

Committee Members

Name	*Profession*	*Capacity*	*Present*
Dr. Derek James Crawford	Consultant Surgeon (Vice-Chairman)	Expert	Yes
Mr. David Owen	Retired Chief Constable (Chairman)	Lay +	Yes
Dr. Philip Wayman White	General Practitioner	Expert	Yes

In attendance

Name	*Position (or reason for attending)*
Dr. Rossela Roberts	Committee Co-ordinator

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol
R&D Internal Review P

Ysbyty Gwy
Clinical Academic
North Wales Clinical S
Bangor, Gwy
LL57

Telephone/Facsimile: 01248 - 384
Email: Rossela.Roberts@wales.n

PRIVATE & CONFIDENTIAL
Miss Gill Toms
PhD Student
School of Psychology
Brigantia Building, Penrallt Road
Bangor, Gwynedd
LL57 2PW

11 March 2011

Dear Miss Toms,

RE: Amendment Review:

Toms 10/WNo01/48	Family-Centred Care Giving and Well Being in a Specialist Children' Service: Linking process with Outcome.

Documents reviewed:	Version	Date
Notice of Amendment Form	-	03/01/2011
Protocol	-	-

The Committee discussed the amendment and is satisfied with the scientific justification for this amendment, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the amendment.
I have pleasure in confirming that the R&D Internal Review Panel (Bangor) has considered the above amendment, and is pleased to grant **approval to continue** at this site.

The amendment does not affect local management approval previously given to this research. As part of the regular monitoring undertaken by the Internal Review Panel you will be required to complete a short progress report.

This will be requested on an annual basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research.

Whilst BCUHB is keen to reduce the burden of paperwork for researchers **failure to produce a report may result in withdrawal of approval.** All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009).

An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely

pp
Dr Richard Tranter
Consultant Psychiatrist
Chairman Internal Review Panel

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COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
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NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

23rd September 2010.

Participant Information Sheet: Focus group

Family-centred care-giving: Linking process with outcome in a Specialist Children's Service (SCS)[1].

Researchers: Gill Toms and Dr Helen Healy (North Wales Clinical Psychology Programme)

Dear Parent,

Invitation

I would like to invite you to take part in a research study. All parents attending the pilot Incredible Years course run by the Specialist Children's Service are being invited to take part. Please read the following information carefully and discuss it with others if you wish. Please contact me if anything is not clear or if you would like more information. Take time to decide whether you wish to take part.

What is the purpose of the study?

We are interested in the relationship between parent's impressions of family-centred care in the Specialist Children's Service, family well-being and child behaviour. As part of this broader study we want to explore parents' experiences of attending an Incredible Years parenting course. We are inviting you to help evaluate what aspects of the course are family-centred and how accessible and useful the course is.

Do I have to take part?

It is up to you whether or not you take part. If you decide to take part you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at anytime without giving a reason. A decision not to take part or to withdraw from the study will not affect the service you will receive from the Specialist Children's Service and will not affect whether or not you can attend the Incredible Years course.

What will it involve?

Taking part will involve doing four things. You will be asked to complete some questionnaires before attending the Incredible Years course and this will take approximately 20 minutes. The researcher will ask to access your child's SCS file to obtain a profile of their developmental abilities. You will be asked to attend the full parenting course. At the end of the course you will be asked to fill in some further

---

[1] Version 3: 24th July 2010

questionnaires which will again take approximately 20 minutes. Lastly, you will be asked to attend a focus group meeting with other participants to discuss perceptions of the course. This discussion will last around an hour and will be audio-taped so that the discussion can be transcribed and analysed for themes. Some quotations from the discussion may be used to represent the themes and opinions expressed. Once the tape has been transcribed, all data files will be deleted. All raw written data will be shredded at the end of the research (September 2011).

What are the possible benefits of taking part?
The results of the study will be presented to the Specialist Children's Service. Understanding more about the needs of families using the Specialist Children's Service and the perceptions they have of the service could help Specialist Children's Services meet families needs.

What are the possible disadvantages or risks of taking part?
There is a very small risk that you might be upset by some of the questions on the questionnaires and in focus group. You do not have to reply to any questions you feel uncomfortable answering. You will be asked to give your time to attend the Incredible Years course, complete the questionnaires and attend the focus group. Travel costs to the focus group will be refunded.

What if something goes wrong?
There are no identified risks in taking part in this study. If you have any concerns you can contact Gill Toms. If you want to make a formal complaint you can contact Professor Oliver Turnbull, Head of the School of Psychology (School of Psychology, Brigantia Building, Bangor University, Bangor, Gwynedd, LL57 2DG).

Will my taking part in the study be kept confidential?
During the Incredible Years course and in the focus group, if you tell the course leader or researcher something which makes them concerned that there might be a risk to you or another person they will try to discuss the matter with you. However, they might then need to inform your child's case manager.

All information collected will be kept confidential and data will be anonymised. After the study all data will be stored securely at the Bangor University in accordance with procedural requirements. Dr Helen Healy will be responsible for this data.

What will happen to the results of the study?
The results of the study will be prepared for publication is a scientific journal and shared with the SCS. You will receive a letter detailing the findings. We would like to use some quotations from the focus group but you will not be identified in any report or publication.

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

Further information

For further information please contact: Gill Toms at email address: [redacted] or telephone [redacted] and I will call you back.

Thank-you.

COLEG IECHYD A GWYDDORAU YMDDYGIAD
COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

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UNIVERSITY

TAFLEN WYBODAETH I RAI SY'N CYMRYD RHAN: Grŵp ffocws
Family-centred care-giving: Linking process with outcome in a Specialist Children's Service (SCS)

Ymchwilwyr: Gill Toms a Dr Helen Healy (Rhaglen Seicoleg Glinigol Gogledd Cymru)

Annwyl Riant,

Gwahoddiad

Hoffwn eich gwahodd i gymryd rhan mewn astudiaeth ymchwil. Mae'r holl rieni sy'n dod i'r cwrs arbrofol Blynyddoedd Rhyfeddol, a gynhelir gan y Gwasanaeth Arbenigol i Blant, yn cael gwahoddiad i gymryd rhan. Cymerwch amser i ddarllen y wybodaeth isod yn ofalus a thrafodwch ei chynnwys gydag eraill os dymunwch. Cysylltwch â mi os oes rhywbeth yn aneglur, neu os hoffech ragor o wybodaeth. Cymerwch eich amser cyn penderfynu a ydych am gymryd rhan neu beidio.

Beth yw pwrpas yr astudiaeth?

Mae gennym ddiddordeb yn y berthynas rhwng argraffiadau rhieni o ofal i deuluoedd yn y Gwasanaeth Arbenigol i Blant, lles teuluoedd ac ymddygiad plant. Fel rhan o'r astudiaeth ehangach hon, rydym eisiau edrych ar brofiadau rhieni o fynd i gwrs magu plant Blynyddoedd Rhyfeddol. Rydym yn eich gwahodd chi i'n helpu i gloriannu pa agweddau ar y cwrs sy'n canolbwyntio ar deuluoedd a pha mor hwylus a defnyddiol ydi'r cwrs.

Oes rhaid i mi gymryd rhan?

Chi sydd i benderfynu a ydych am gymryd rhan ai peidio. Os byddwch yn penderfynu cymryd rhan byddwn yn gofyn i chi lofnodi ffurflen gydsynio. Os byddwch yn penderfynu cymryd rhan, mae gennych hawl i dynnu'n ôl unrhyw bryd heb roi rheswm. Os penderfynwch beidio â chymryd rhan, neu os byddwch yn tynnu'n ôl o'r astudiaeth, ni fydd hynny'n effeithio ar y gwasanaeth y byddwch yn ei gael gan y Gwasanaeth Arbenigol i Blant ac ni fydd yn eich rhwystro rhag mynychu'r cwrs Blynyddoedd Rhyfeddol.

Beth fydd angen i mi ei wneud?

Wrth gymryd rhan gofynnir i chi wneud pedwar peth. Gofynnir i chi lenwi rhai holiaduron cyn mynd ar y cwrs Blynyddoedd Rhyfeddol a bydd hynny'n cymryd tua 20 munud. Bydd yr ymchwilydd yn gofyn am gael mynd at ffeil SCS eich plentyn er mwyn cael proffil o'i (g)alluoedd datblygiadol. Gofynnir i chi fynd i'r cwrs llawn ar fagu plant. Ar ddiwedd y cwrs gofynnir i chi lenwi rhai holiaduron eraill, a fydd eto'n cymryd tua 20 munud. Yn olaf, gofynnir i chi fynd i gyfarfod grŵp ffocws gyda chyfranogwyr eraill i drafod eich canfyddiadau o'r cwrs. Bydd y drafodaeth hon yn para tua awr a chaiff ei recordio ar dâp sain fel y gellir trawsgrifio'r drafodaeth a'i dadansoddi i weld pa themâu sy'n codi. Gall rhai dyfyniadau o'r drafodaeth gael eu defnyddio i gynrychioli'r themâu a'r farn a fynegir. Unwaith y caiff y tâp ei drawsgrifio, caiff yr holl ffeiliau data eu dileu. Bydd yr holl ddata crai ysgrifenedig yn cael eu dinistrio ar ddiwedd yr ymchwil (Medi 2011).

Beth yw manteision posibl cymryd rhan?

Cyflwynir canlyniadau'r astudiaeth i'r Gwasanaeth Arbenigol i Blant. Gall deall mwy am anghenion teuluoedd sy'n defnyddio'r Gwasanaeth Arbenigol i Blant, a'r canfyddiadau sydd ganddynt o'r gwasanaeth, helpu'r Gwasanaethau Arbenigol i Blant ddiwallu anghenion teuluoedd.

Beth yw'r anfanteision neu'r risgiau posibl wrth gymryd rhan?

Mae yna risg fach iawn y gallai rhai o'r cwestiynau yn yr holiaduron ac yn y grŵp ffocws darfu arnoch. Nid oes raid i chi ateb unrhyw gwestiwn sy'n gwneud i chi deimlo'n annifyr. Gofynnir i chi roi eich amser i fynd i'r cwrs Blynyddoedd Rhyfeddol, llenwi'r holiaduron a mynd i'r grŵp ffocws. Caiff costau teithio i'r grŵp ffocws eu had-dalu.

Beth os aiff rhywbeth o'i le?

Ni ragwelir bod unrhyw beryglon yn gysylltiedig â chymryd rhan yn yr astudiaeth hon. Os oes gennych unrhyw bryderon gellwch gysylltu â Gill Toms. Os byddwch eisiau gwneud cwyn ffurfiol, gellwch gysylltu â'r Athro Oliver Turnbull, Pennaeth yr Ysgol Seicoleg, Adeilad Brigantia, Prifysgol Bangor, Bangor, Gwynedd, LL57 2DG.

Fydd y ffaith fy mod yn cymryd rhan yn yr astudiaeth yn cael ei chadw'n gyfrinachol?

Yn ystod y cwrs Blynyddoedd Rhyfeddol ac yn y grŵp ffocws, os byddwch yn dweud rhywbeth wrth arweinydd y cwrs neu'r ymchwilydd a fydd yn gwneud iddynt boeni bod risg i chi neu i rywun arall o bosib, byddant yn ceisio trafod y mater gyda chi. Fodd bynnag, efallai y bydd angen iddynt roi gwybod wedyn i reolwr achos eich plentyn.

Bydd yr holl wybodaeth a gaiff ei chasglu yn cael ei chadw'n gyfrinachol a bydd data yn ddi-enw. Ar ôl i'r astudiaeth ddod i ben caiff yr holl ddata eu cadw'n ddiogel ym Mhrifysgol Bangor yn unol â'r gofynion. Dr Helen Healy fydd yn gyfrifol am y data hyn.

Beth fydd yn digwydd i ganlyniadau'r astudiaeth?

Caiff canlyniadau'r astudiaeth eu paratoi i'w cyhoeddi mewn cyfnodolyn gwyddonol a'u rhannu â'r SCS. Byddwch yn derbyn llythyr yn amlinellu'r darganfyddiadau. Hoffem ddefnyddio rhai dyfyniadau o'r grŵp ffocws ond ni ddatgelir pwy ydych mewn unrhyw adroddiad neu gyhoeddiad.

Gwybodaeth bellach

Gwaetha'r modd, nid yw'r holiaduron a ddefnyddir yn yr astudiaeth ar gael yn Gymraeg. Gobeithiwn y byddwch yn fodlon llenwi'r holiaduron yn Saesneg. I gael gwybodaeth bellach, cysylltwch â: Gill Toms yn y cyfeiriad e-bost: [redacted] neu ffoniwch: [redacted] ac fe wnaf eich ffonio'n ôl.

Diolch yn fawr.

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COLLEGE OF HEALTH & BEHAVIOURAL SCIENCES

YSGOL SEICOLEG
SCHOOL OF PSYCHOLOGY

RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME

PRIFYSGOL
BANGOR
UNIVERSITY

Family-centred care-giving: Linking process with outcome in a Specialist Children's Service[1].

Researchers: Gill Toms and Dr Helen Healy

Consent form.

Please initial in the box.

1. I confirm I have read and understood the participant information sheet (date/ version). I have had the opportunity to ask questions and have received satisfactory answers. ☐
2. I understand participation is voluntary. I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected. ☐
3. I give permission for the researcher to access my child's Specialist Children's Service file to obtain a profile of their developmental abilities. ☐
4. I agree to complete questionnaires at the start and end of the Incredible Years course. ☐
5. I agree to attend the focus group and consent for this to be audio-taped. ☐
6. I agree that quotations from the focus group can be reported. Nothing that identifies me will be reported. ☐
7. I understand the limits of confidentiality. The researcher will contact my child's case manager if they are concerned about my or my family's safety. They will try to talk with me before doing this. I agree that my child's case manager can be told that I am taking part in the study. My child's case manager is.................... ☐

Signed................................ Date.............................

Name (please print) ....

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[1] Version 3: 20th Aug 2010

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Family-centred care-giving: Linking process with outcome in a Specialist Children's Service

Ymchwilwyr: Gill Toms a Dr Helen Healy

FFURFLEN GYDSYNIO

Llofnodwch y bocs

1. Rwy'n cadarnhau fy mod wedi darllen a deall y daflen wybodaeth (dyddiad a fersiwn). Rydw i wedi cael cyfle i ofyn cwestiynau ac wedi cael atebion boddhaol. ☐
2. Deallaf fy mod yn cymryd rhan o'm gwirfodd. Gallaf dynnu'n ôl unrhyw bryd heb roi reswm ac heb i hynny effeithio ar fy ngofal meddygol neu hawliau cyfreithiol. ☐
3. Rwy'n rhoi caniatâd i'r ymchwilydd fynd at ffeil fy mhlentyn yn y Gwasanaeth Arbenigol i Blant i gael proffil o'i (g)alluoedd datblygiadol. ☐
4. Rwy'n cytuno i lenwi holiaduron ar ddechrau a diwedd y cwrs Blynyddoedd Rhyfeddol ☐
5. Rwy'n cytuno i fynd i'r grŵp ffocws ac i hwnnw gael ei recordio ar dâp sain. ☐
6. Rwy'n cytuno y gellir adrodd ar ddyfyniadau o'r grŵp ffocws. Ni chynhwysir dim a fydd yn datgelu pwy ydwyf. ☐
7. Rwy'n deall cyfyngiadau cyfrinachedd. Bydd yr ymchwilydd yn cysylltu â rheolwr achos fy mhlentyn os yw'n bryderus am fy niogelwch i neu ddiogelwch fy nheulu. Bydd yn ceisio siarad â mi cyn gwneud hyn. Rwy'n cytuno i reolwr achos fy mhlentyn gael gwybod fy mod yn cymryd rhan yn yr astudiaeth. Rheolwr achos fy mhlentyn yw .... ☐

Llofnod ....

Enw (priflythrennau) ....

Dyddiad ....

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BANGOR
UNIVERSITY

29th November 2010

Case Managers name,
Specialist Children's Service.

Dear ....,

Re study: Family-centred care-giving: Linking process with outcome in a Specialist Children's Service[1]

Researchers: Gill Toms and Dr Helen Healy (North Wales Clinical Psychology Programme)

This is to inform you that Mr/ Mrs/ Ms .... is taking part in the above study. They have agreed to complete questionnaire measures before and after the end of the Incredible Years course they are attending. They have also agreed to attend a focus group to discuss their perceptions of the course. They are aware of the limits to confidentiality and that I will need to inform you if any risks to themselves or others are reported during the study.

Yours sincerely,

Gill Toms
Trainee Clinical Psychologist and primary researcher

Dr Helen Healy,
Clinical Psychologist and research supervisor

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[1] Version 1: 10th June 2010

Amendments to the protocol

In the questionnaire survey, following the recruitment protocol resulted in few questionnaires being returned. To maximise the number of returns, two changes were made to the original research plan:

1. The number of questionnaires was reduced. Participants were only asked to complete the demographic information, the Measure of the Processes of Care, the Family Impact Questionnaire and the 12-item General Health Questionnaire. This reduced the time burden on participants and meant it was feasible for the researcher to complete questionnaires with parents in clinic waiting rooms if they requested this assistance.
2. Participants were approached at nursing groups provided by the Specialist Children's Service and plans were made to attend a parent support group. Ethical approval was obtained for these additional recruitment methods.

However, it was recognised that these protocol changes may not be sufficient to increase the rate of participation. Therefore, a secondary data analysis was conducted to explore the service use of children with learning disability. This provided context to the focus group responses and provided another angle to the exploration of family-centred care.

The amendments to the questionnaire survey did increase the number of responses. However, only twenty-three questionnaire packs were completed and due to the amended recruitment methods, the sample was potentially biased: only well-engaged, motivated parents were likely to have accessed the survey. It was therefore decided to present the focus group and secondary data analysis in this thesis. The questionnaire survey data was used to feedback information to the service, as agreed in the ethics protocol.

Social Demographic Information

Please complete the following information:

Your gender *(Please circle)*:

Male Female

Your age *(please circle)*:

18-20 21-25 26-30 31-35 36-40 41-45 46-50 51-55 55+

Your marital status *(Please circle)*:

Married/ Civil partnership Single Co-habiting Divorced Widowed

Your employment status *(Please circle)*:

Unemployed Employed Student

Your highest level of education *(Please circle)*:

No examinations taken GCSE or equivalent A-level or equivalent Degree

Post-degree level

Please state your ethnicity: ……………………………………………………………

What is your first language: …………………………………………………………

How many children do you have? ……………………………………………………

Please complete the following questions about your child/ children who access the Specialist Children's Service:

Child's age: …………………………………

Child's gender *(Please circle)*: Male Female

Child's diagnosis *(if known)*: ……………………………

Thank-you

Pre-course measure of parent's aims

In the space below please list three problems you would like to see changed by attending the Incredible Years course. Mark on the line underneath each problem to show the current severity of the problem.

PROBLEM
ONE:……………………………………………………………………………………………………
………
………

Current severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

PROBLEM
TWO:……………………………………………………………………………………………………
………
………

Current Severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

PROBLEM
THREE:…………………………………………………………………………………………………
………
………

Current Severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

Strengths and Difficulties Questionnaire 3/4

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all the items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last *month.*

	Not True	**Somewhat True**	**Certainly True**
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often argumentative with adults	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Can stop and think things out before acting	☐	☐	☐
Can be spiteful to others	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
☐	☐	☐	☐

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

- Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

- Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

- Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Signature .... Date ....

Mother/Father/Other (please specify:)

Thank you very much for your help

Strengths and Difficulties Questionnaire 4-16

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all the items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last *month.*

	Not True	Somewhat True	Cert Tr
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

	No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
	☐	☐	☐	☐

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

	Less than a month	1-5 months	6-12 months	Over a year
	☐	☐	☐	☐

- Do the difficulties upset or distress your child?

	Not at all	Only a little	Quite a lot	A great deal
	☐	☐	☐	☐

- Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

- Do the difficulties put a burden on you or the family as a whole?

	Not at all	Only a little	Quite a lot	A great deal
	☐	☐	☐	☐

Signature .... Date ....

Mother/Father/Other (please specify:)

Thank you very much for your help

Post-course measure of parent's aims

Before you started the Incredible Years course we asked you to list three problems you would like to change. These problems are listed below. Please rate the current severity of each problem.

YOU WROTE THAT PROBLEM ONE
WAS:...
....
....

Current severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

YOU WROTE THATE PROBLEM TWO
WAS:..
....
....

Current Severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

YOU WROTE THAT PROBLEM THREE
WAS:..
....
....

Current Severity:

____

0 1 2 3 4 5 6 7 8 9 10
Not a problem Very severe problem

The Client Satisfaction Questionnaire

Please help us improve our *service* by answering some questions about the services you have received at the *Specialist Children's Service.* We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions. Thank you very much, we appreciate your help.

PLEASE CIRCLE YOUR ANSWER:

1. **How would you rate the quality of the service you received?**

4	3	2	1
Excellent	Good	Fair	Poor

2. **Did you get the kind of service you wanted?**

1	2	3	4
No, definitely not	No, not really	Yes, generally	Yes, definitely

3. **To what extent has our *service* met your needs?**

4	3	2	1
Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met

4. **If a friend were in need of similar help, would you recommend our *service* to him/ her?**

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

5. **How satisfied are you with the amount of help you received?**

1	2	3	4
Quite dissatisfied	Indifferent or mildly dissatisfied	Mostly satisfied	Very satisfied

6. **Have the services you received helped you to deal more effectively with your problems?**

4	3	2	1
Yes, they helped a great deal	Yes, they helped somewhat	No, they really didn't help	No, they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the service you received?

4	3	2	1
Very Satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied

8. If you were to seek help again, would you come back to our service?

1	2	3	4
No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely

WRITE COMMENTS BELOW:

Appendix I: Empirical Paper B data analysis

Focus Group: Moderators Guide

Pre-plan seating and make a map before the group starts of where people are sitting.

1. Introduction

- Thank-you for coming.
- The purpose of talking together is to find out people's experiences of attending the IY course.
- The IY course is said to be family-centred and it this aspect I am particularly interested in.
- Everyone's views are welcomed.
- I will be writing brief notes as we talk just to help me remember key things that were said.
- There are just a few guidelines to help make the meeting run smoothly
    - If one person could talk at a time because the meeting is being taped and this will really help me when I come to listen to the tape
    - As we only have a limited amount of time I might need to move on the discussion at points to make sure I cover everything
    - What is said in the room should stay in the room. When I write up what is said I will make sure it is anonymous. The only reason I will share what is said by someone in the room is if I am concerned there is a risk to them or someone else.
    - I'm sure we'll all be respectful of other people's views and opinions
- Does anyone have any questions? It's fine to ask questions as we go along.

2. Warm up

- Maybe we could just go around the table and introduce ourselves (first names- me first to model).

3. Clarification of terms

- So the course I'm asking you about today is the one you've just attended which was led by the Specialist Children's Service.
- As I said I am interested in family-centred care which is all about how services meet the needs of individual families.

4. Easy opening questions

General prompts: Can you tell me a bit more
Could you explain that further
Can you give me an example

- What did you like most about the course?
- What did you like least about the course?

Prompts to use: What did you think of the topics covered?
What did you think of the different presentation formats?
(E.g. Role plays, discussion, videos, handouts)
What topics would you like to have seen included?

5. Harder questions

General prompts: Can you tell me a bit more
Could you explain that further
Can you give me an example

- What did you expect the course to be like and what did you hope to gain from it?

Prompts to use: How were these expectations met?

- How did you feel in the group?

Prompts to use: How did you find talking in the group?
How did you find the size of the group?

- How did you find putting the things you learnt into practice?

Prompts to use: Was anything difficult?
Can you give some examples of when you tried out the skills?

- How did the course advice fit with what other workers in the service have suggested?
- How has the course impacted on your relationship with your child/ children?

Prompt to use: How did the course influence your parenting?

6. Wrap up

- Summarise what been said
- Highlight what I think main themes are
- Sorry about any conversation points or ideas we didn't have time to fully discuss

7. Member check

- I'd just like to check you agree with my summary by asking everyone in turn to briefly say why you would or wouldn't recommend the course to a friend?

8. Closing

- Thank-you again for coming… it's really appreciated
- Just a reminder to keep what we talked about confidential
- Does anyone have any questions?

Summary of the framework analysis conducted

1. Familiarisation

Reviewing the recording and transcript, the group was somewhat reticent at first, but by the end most respondents were more forthcoming. Exploring how the course co-ordinated with other services and advice from other professionals was difficult and this question was not answered directly by any respondent. Similarly, when asked about how the course impacted on their relationship with their child, respondents primarily discussed the impact on other children at home. Subsequent readings identified that respondents tended to be protective towards the course and facilitators, implying there could be some bias in their responses. Respondent three's response to the member check highlights this response pattern.

Key/ recurrent ideas listed after first four readings:

- Meeting others in the same situation
- Social support
- Isolated, unseen needs
- Services not linking up
- Inconsistent expectations
- Gaining and sharing information- ? empowerment
- Parents of children with Learning Disability (LD) have distinct issues
- Differences within the group
- Being treated as an individual family or not
- Adapting advice to suit the family/child
- Taking pride in the child
- Self-change
- Choosing your battles
- Child change
- An individual relationship- not long-term
- Interpersonal and group attributes- linking to trust
- Responsiveness of services/ course
- Looking for hope
- Goals being met or not
- Impact on the family
- Having timely access to services
- Highlighting the problems
- Practical problems
- Unshared learning
- Emotional reactions
- Changes are slow
- A positive focus
- An uncertain future
- Preparation

Exploring recurrent ideas and the links between these generated a list of emergent themes:

Meeting others in a similar situation
- Families with children who have a LD have unique needs
- Idea of 'them' and 'us'
- The 'us' is not entirely unitary
- Sense of isolation as some problems are unseen by people outside the family
- Social support

Gaining and sharing information
- Benefit of specific information
- Benefit of receiving support from parents who have similar experiences

Features of the group
- Responsiveness
- Treated as individual families
- Services do not link up
- The group atmosphere
- Interpersonal skills of the facilitators

Outcomes
- Managing uncertain futures- with a positive focus or when goals are not met
- Family impact of the course and child with LD
- Change can be slow, but parents take pride in the child
- Other people's reactions- to the child with LD and Incredible Years (IY) techniques
- Self-change: choosing your battles, highlighting the issues
- Emotional reactions

2. Identifying a thematic framework

The transcript was re-read and a framework for analysis was used which comprised three elements:

1.Areas of interest identified in the literature were investigated. Not every respondent commented on every point but views on the acceptability of the IY course and perceptions of FCC were evident in responses that touched on respondents views on the:
- Psycho-education and practical assistance provided
- Partnerships formed
- Relevance and specificity of the IY course
- Ability of the IY course to modify concerns
- Coordination with service provision.

2.Emergent ideas in step one were refined. Three themes were distinct from the areas of interest identified in the literature.

3.As the transcript was re-read deeper meanings of what respondents' said were interpreted and the emerging pattern and juxtaposition of themes was noted. Four analytic themes were identified.

3. Indexing

The following index was developed and used to label the transcript.

Research Question Items

1. Acceptability of the IY course
    - 1.1. IY course is acceptable
    - 1.2. Caveats to the acceptability of the IY course

2. Psycho-education
    - 2.1. Psycho-education perceived as good
    - 2.2. Problems with the information
    - 2.3. Adapting the information to suit family circumstances (emergent theme)
    - 2.4. Receiving information/ advice from other parents (emergent theme)

3. Practical assistance
    - 3.1. Assistance perceived as good
    - 3.2. Problems with implementing advice/ techniques

4. Relevance and specificity
    - 4.1. IY course perceived as meeting needs
    - 4.2. IY course perceived as lacking
    - 4.3. Services perceived as meeting needs
    - 4.4. Services perceived as lacking
    - 4.5. Unmet needs, which professionals do not see (emergent theme)

5. Modifying concerns
    - 5.1. IY course modified concerns
    - 5.2. Barriers to modifying concerns

6. Facilitative and enabling partnership
    - 6.1. Perceived in IY
    - 6.2. Perceptions of this lacking on IY course
    - 6.3. Perceived in services
    - 6.4. Perceptions of this lacking in services

7. Co-ordinated provision
    - 7.1. Perceptions of service co-ordination
    - 7.2. Lack of co-ordination

Emergent themes

8. Social support
    - 8.1. Perceived as present in IY course

8.2. Caveats to the IY course providing social support

9. Self-change
    9.1. Positive changes
    9.1.5 Negative changes
    9.2. Acceptance and adjustment
    9.3. Choosing the changes/ battles

10. Family impact
    10.1. IY course positive impact on the family
    10.2. IY course negative impact on the family
    10.3. Positive impact of child with LD on the family
    10.4. Negative impact of child with LD on the family

Analytical themes

11. Power dynamics
    11.1. Families' needs when children have LD
    11.2. Ownership of decisions
    11.3. Empowerment
    11.4. Lack of power

12. Responsiveness and pro-active services
    12.1. IY course responsive
    12.2. Services responsive
    12.3. Services lacking responsiveness
    12.4. Needing to wait

13. Managing an uncertain future
    13.1. Adaptive coping
    13.2. Narrative coping

14. Not overlooking the child
    14.1. Taking pride in the child
    14.2. Advocacy

3. Charting

Initially data was charted according to the index and then chart was colour coded to highlight which themes were related by more than one respondent. Colours also illustrated when two opposite views referred to the same theme. When considering power dynamics, again the moderator's influence seemed important to acknowledge because of respondents' apparent reticence in voicing criticisms. It was also noted that the transcript contained examples of respondents' advocating for their child (See chart).

4. Mapping and interpretation

To present the key themes and illustrative quotes succinctly, information was presented in sequence from superficial IY course feedback to deeper reflections about FCC.

Additionally, key feedback for the service was highlighted (See 'The acceptability of the IY course as part of FCC').

Additional Analysis

Supervision sessions

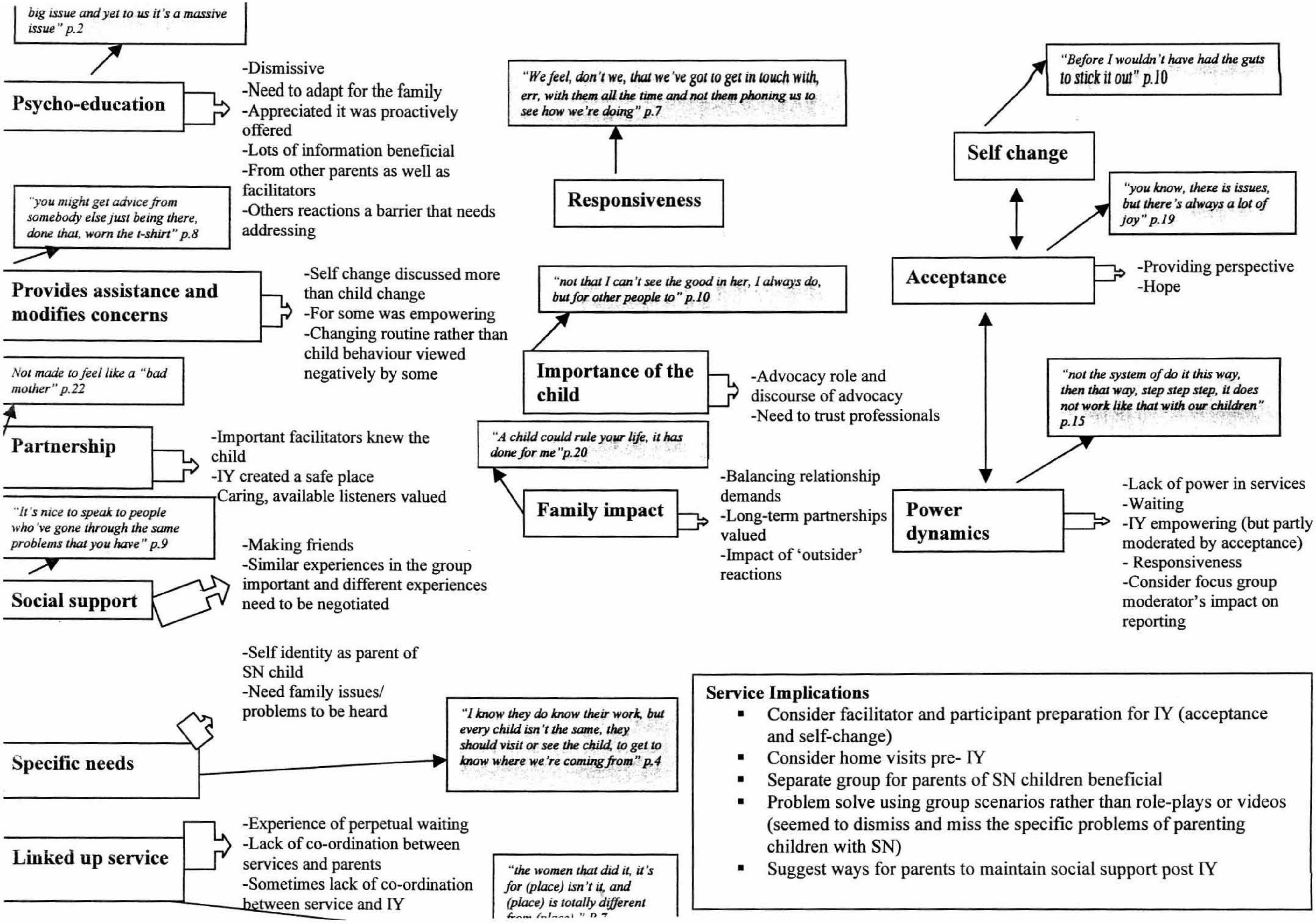
Discussed the dual role of the researcher in the focus group and some of the tensions and benefits this brought. Also reflected on how group processes and dynamics may have influenced the data. When writing the research paper it was decided to change the theme titles so that they better fitted the data they represented. The validity of these new theme titles was discussed in supervision.

Example of Charting: Framework Analysis step 4.

Responsiveness and proactive services

Respondent	IY course responsive	Services responsive	Services lacking responsiveness	Waiting
1				"I'm still waiting to see other people, so" (p14) -"he's just going to take his time. I'm going to give him that time to…" (p8)
1.5	Facilitators tried to meet the needs of the group (p4)		"We've got to get in touch with err, with them all the time and not them phoning us…" (p7)	Talked of waiting for results: "..things are not moving quick enough" (p7) -Idea of child change taking time; "you know, more than two, three days for it to sink in…" (p14)
3	Facilitators responded to what the group wanted (p4) -Could get help quickly and that made things better (p6) -Facilitators on the course were "readily available for help" (p19) -Facilitators interpreted the course materials to help the group (p22)	"They are definitely more responsive, more flexible…they do look at us as a family and a child, and try and work around what we want rather than fit us into a system" (p15) talking about health service -Health services were seen to respond quite quickly (p15) -Considered health service proactive because "they	Idea that services did not respond as quickly as facilitators on IY course so there could be a long wait between trying a strategy and getting further feedback (p6) -"..they have a way and you fit their way or you don't" "it's rigid and erm, even other courses, they're trying to sort of push into a way" (p15)	Idea normally had to wait for help (p19) -Course enabled regular contact so things could be "speeded up" (p6) and there were perceived benefits of being able to do something straightaway; "the fact you were coming every week meant that perhaps you did speed up what you were doing more than you might have normally" -Idea that some services

		came to us and asked do you want something, do you need this" (p16) -Intervention by nurse was offered, they didn't need to ask (p16)		responded slowly unless the parent 'forced' them (p15)
5			"so they, they just go on numbers, don't they, and the age and that's it. Not your child's needs". Talking about the education service (p16)	Complained she was still waiting to see the nurse (p16)
6				In example about child's absconsion from school she indicated she was still waiting for answers (p17,18)



big issue and yet to us it's a massive issue" p.2

Psycho-education

-Dismissive
-Need to adapt for the family
-Appreciated it was proactively offered
-Lots of information beneficial
-From other parents as well as facilitators
-Others reactions a barrier that needs addressing

"you might get advice from somebody else just being there, done that, worn the t-shirt" p.8

Provides assistance and modifies concerns

-Self change discussed more than child change
-For some was empowering
-Changing routine rather than child behaviour viewed negatively by some

Not made to feel like a "bad mother" p.22

Partnership

-Important facilitators knew the child
-IY created a safe place
Caring, available listeners valued

"It's nice to speak to people who've gone through the same problems that you have" p.9

Social support

-Making friends
-Similar experiences in the group important and different experiences need to be negotiated

-Self identity as parent of SN child
-Need family issues/ problems to be heard

Specific needs

"I know they do know their work, but every child isn't the same, they should visit or see the child, to get to know where we're coming from" p.4

Linked up service

-Experience of perpetual waiting
-Lack of co-ordination between services and parents
-Sometimes lack of co-ordination between service and IY

"the women that did it, it's for (place) isn't it, and (place) is totally different from (place)." P.7

"We feel, don't we, that we've got to get in touch with, err, with them all the time and not them phoning us to see how we're doing" p.7

Responsiveness

"not that I can't see the good in her, I always do, but for other people to" p.10

Importance of the child

-Advocacy role and discourse of advocacy
-Need to trust professionals

"A child could rule your life, it has done for me" p.20

Family impact

-Balancing relationship demands
-Long-term partnerships valued
-Impact of 'outsider' reactions

"Before I wouldn't have had the guts to stick it out" p.10

Self change

"you know, there is issues, but there's always a lot of joy" p.19

Acceptance

-Providing perspective
-Hope

"not the system of do it this way, then that way, step step step, it does not work like that with our children" p.15

Power dynamics

-Lack of power in services
-Waiting
-IY empowering (but partly moderated by acceptance)
- Responsiveness
-Consider focus group moderator's impact on reporting

Service Implications

- Consider facilitator and participant preparation for IY (acceptance and self-change)
- Consider home visits pre- IY
- Separate group for parents of SN children beneficial
- Problem solve using group scenarios rather than role-plays or videos (seemed to dismiss and miss the specific problems of parenting children with SN)
- Suggest ways for parents to maintain social support post IY

Appendix II: Review data analysis

Example of review paper analysis
Empowerment

Paper	Authors' themes	Content	Reflections
Minke & Scott (1995)	Staff reactions to parent participation -Toward involvement and collaboration	"It doesn't have a long-term effect if you can't empower the parents to be able to advocate for their child." This quote was balanced against professional concerns that some parents couldn't be relied on to act in their child's best interests. Relationships were strained when professionals were anxious about parents controlling relationships but there was a different relationship when there was mutual trust and respect. In their discussion they provided a model to facilitate staff's capacity to view parental assertiveness and control as positive characteristics and highlighted the possible impact of SES differences between parents and professionals.	Cross-over with power dynamics theme.
Lindblad et al (2005b)	Grounded in a personal and professional philosophy about the task	Parental participation is a pre-requisite for accomplishing tasks but professionals bear the main responsibility for the relationship	Discussion quite paternalistic towards parents
	Confident it is always possible to help/ Trustworthy partner of parents	Trust is mutual- trust parents have capacity to care for their child	Crossover with power dynamics and interpersonal factors.
	Enabling parents to gain competence and confidence in parenthood	Enabling cant take place unless professionals are viewed as trustworthy partners	
	Enabling parents to gain competence and confidence as their child's carer	Professionals share knowledge with sensitivity to the family and parents own learning styles. Discussion about how to support families.	
	Promote parental strengths and authority	Listen and confirm parents decisions, ask for their opinions and respect their opinions and desires. Do not cross the boundary between professional and parent domains.	
Todd &	Good mothers and	Mums did not feel their qualities and	Crossover with

Jones (2003)	bad professionals Muted voices Fighting talk: Subsequent professional relationships	competencies were always legitimized by professionals. Contact with professionals was summarised as judgemental disempowering and anxiety raising: "I felt totally inadequate, really, and I was made to feel that by these health professionals" "But I'm not the professional, I don't know how to do things, they're supposed to" Strong theme of continued disempowerment- idea of impression management. In discussion said mums motivated by their child's needs (vs empowered by partnership) and they highlighted that advocating for parents rights is often missing in professional literature	power dynamics The other side of the coin to Lindblad et al's paper.
James & Chard (2010)	The early years- a new experience Empowerment: Now, I'm ready	Identified that parents needed to be ready to act as advocates: "for the first year or two I needed direction" Didn't link empowerment to staff- just talked of feeling better prepared to participate with time. Example of disempowerment given: "We've never met any of the management staff, we wouldn't know who to go to if we had an idea" In discussion recommended including parents in all aspects of service delivery	Idea of being ready for empowerment touched on in Todd & Jones ? empowerment and advocacy linked.
Fereday et al (2010)	The role of advocacy in General Health Practitioner-parent partnerships	Parents fight to redress imbalances in the PPP. Advocating can lead to parents being viewed as "pushy": "And half the time I think they cringe every time they see me walking in the door"	Could include under advocacy but fits with Todd & Jones ideas about the flip side to empowerment.

Categorising author's themes into the higher order themes obtained from the analysis

Power dynamics (23)

Collaboration: the middle ground
Negotiating custody: Getting in, Getting out
Strategies for striving for therapeutic relationships (sub-themes; balancing, questions and questioning, reading the cues, managing sessions, consequences, managing uncertainty)
Disconnection between role of parent at home vs parent in PICU
Gaining confidence as a parent and being obstructed from gaining confidence as a parents (sub-theme; being acknowledged as the child's carer and being ignored as the child's carer)
Good mothers and bad professionals
Muted voices
Fighting talk: Subsequent professional relationships
Genuine sharing of decision making with service providers
The ready availability of pertinent information
Staff reactions to parent participation (sub-themes; attitudes toward involvement and collabortion, characterization of parents, expectations of parents)
Being humble in the face of parents knowledge and experience of the child

Empowerment (5)

Empowerment: Now, I'm ready
Being confident it is always possible to help
Enabling parents to gain competence and confidence in parenthood (sub-themes; Enabling parents to gain competence and confidence as their child's caregiver, promoting parental strengths and authority)

Advocacy (1)

Disciplined advocates

Interpersonal factors (21)

Striving for therapeutic relationships (sub-themes; context of uncertainty, conditions, variabilities)
General Health Practitioner- parent partnerships (sub-themes; respect, trust)
Communication support
Nurse-parent relationships
The supportive relationship
Effects and flexibility of family supports
Predictions for the trajectory of care
Nature of valued social work support
Impact of positive behavioural support
Personal parent-staff relationships in encouraging active participation (sub-themes; parent-staff bond, change over time)
Pre-helping attitudes and beliefs*
Helping behaviours*
Post help responses and consequences*
Behaviour outcomes*
Being a trustworthy partner

*Titles from model rather than themes- but presented data to match headings

Consideration for the child (9)
Creating a space for the child's involvement
Acknowledging variability in child preferences
Negotiating children's age and development
Know the child's baseline
The child is acknowledge as valuable and the child is not acknowledged as valuable (sub-themes; having a child who is met as a person and having a chid who is neglected as a person, having hope for the child's future and being left alone in uncertainty and confusion about the child's future, having a child who is seen as worthy of help and having a child who is seen as unworthy of help)
Commitment to the child as an important person and one who is worthy of engagement

Emotional support (12)
Gain confidence as a parent and being obstructed from gaining confidence as a parent (sub-themes; being acknowledged as a person and being neglected as a person, having ones worries eased in daily life and not finding any ease in daily life)
Parents' feelings about support
Support as a loss
Journey to accepting support
Having positive prospects for the family's future
Acceptance and denial
Definitive diagnosis vs the embrace of paradox
Positive illusions and the embrace of paradox
Being sensitive to parents' vulnerability
Attending to parents as persons

Unable to categorise from the title (3)
The early years; a new experience
Parents on the centre, on relationship between centre and services
Professionals on the centre, on relationships between centre and services

Other (15)
GHP-parent partnership- provision of professional services
Integrating and bridging multiple services
PICU admission does not equate with respite
High-stakes learning environment
Heterogeneity within group
Lack of fit with acute care model
Prior experience of hospital care
Parents' perceptions of nurses and nursing
Disability and the parent
Types of family support
Barriers to the flexible payment scheme
Unmet needs from the flexible payment scheme
Means of access to social services
Impact of problem behaviour on the family
Problems about individual family service plan processes- unshared information

Appendix III: Word Counts

Word Counts

Thesis Title:	8
Overall Abstract:	245
Review Paper:	
Abstract:	215
Article:	5070
References:	1167
Tables/ Figures:	1490
Empirical Paper A:	
Abstract:	148
Article:	3171
References:	712
Tables:	546
Empirical Paper B:	
Abstract:	220
Article:	4102
References:	748
Tables:	252
Discussion Paper:	
Article:	3302
References:	811
Ethics:	
Information sheets:	1404
Consent forms:	358
Amendments:	256
Appendix:	
I	2575
II	1159
III	79

Overall word counts:

Papers excluding references, figures, tables and appendixes: 16,481

Papers including references, figures, tables and appendixes: 28,038